THE MOST DIFFICULT TEACHABLE MOMENT:

AUTOPSY CONSENTING

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ABSTRACT

Medical and clinical discoveries through autopsies have informed hundreds of studies elucidating pathophysiological developments of diseases, which are crucial for improving medical treatment. At Johns Hopkins Hospital (JHH), all families of patients who have been inpatients within the past year have the right to an autopsy. This service requires consent of the deceased patient's next-of-kin. It is important for clinicians to provide empathy while effectively communicating the medical significance and benefits an autopsy can provide for the patients' families, when asking for consent. However, clinicians frequently find themselves unprepared for this important conversation for two main reasons: 1) lack of training opportunities and 2) lack of educational materials organizing the process of asking for autopsy.

To meet the need for educational material and training opportunities, we envisioned a systematic learning experience with three main components: 1) a training module webpage, 2) a quick reference mobile app, and 3) a printed pocket guide. Contents for each component were selected in consultation with a JHH pathologist and clinicians experienced in obtaining autopsy consent. The webpage includes well organized information and interactive simulations to help clinicians learn and retain the material. This knowledge is reinforced by utilizing a mobile app, which enables easy access to necessary information right before or while the clinician is requesting an autopsy consent from the patient's family. Finally, the hand-held pocket guide provides visual support for not only the clinicians, but also for the families when determining the correct next-of-kin, discussing how the autopsy will affect the funeral, and informing the next steps families should prepare for once their consent is given.

Through the novel use of Standardized Patients and interactive-media-building software alongside 2D illustrations, we have developed prototype resources designed for effective information delivery. This opportunity has shed light on the potential use of such hybrid media in

creating highly effective medical visualization resources, in this case, to improve the communication in requesting autopsy consent at the Johns Hopkins Hospital.

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1. Autopsy

The history of autopsy

Throughout history, autopsies have provided valuable knowledge in human anatomy, pathophysiology, and epidemiology. By examining a patient's body after death, physicians are able to correlate clinical symptoms to physiological and anatomical observations. Autopsies can not only provide or confirm the cause of death for the family, but also help advance medical knowledge and development.

From the early autopsies performed by Herophilus of ancient Greece, Morgagni during the Renaissance, and Rokitansky in 20th century, autopsy has evolved with multiple civilizations and through devastating pandemics, while continuously contributing to the breakthroughs of modern medicine (Hooper, 2019). Increased media exposure with dramatic portrayals of the postmortem examination may have contributed to general public misconceptions about autopsy; it should not be forgotten that an autopsy is a diagnostic medical procedure done with respect *for* a patient not *to* a body (Hooper, 2020).

Autopsies in the US

Autopsy rates - the number of autopsies per number of hospital deaths - in the US were as high as 80% in 1955, and plummeted to approximately 45% in 1975 (Shojania & Burton, 2008). Since then, autopsy rates, including forensic cases, fell to approximately 8% in 2018 (Goldman, 2018) and have continued to drop. With the emergence of COVID-19 in 2019, demand for autopsies has increased; however, the combination of this increased demand with fewer hospitals and pathologists equipped to perform the task, has led to an autopsy shortage in 2021 (Arnold, 2021).

Autopsy at the Johns Hopkins Hospital

At Johns Hopkins Hospital (JHH), all families of patients who have been inpatients within the past year have the right to an autopsy, including all who die in the Emergency Department or as inpatients. Autopsies at JHH are supervised by pathologists, who are medical doctors trained to examine and validate the effects of disease. Since its establishment in 1889, the JHH Autopsy Service has performed more than 53,000 autopsies (Johns Hopkins Pathology, 2021). Medical and clinical discoveries at the JHH have informed hundreds of studies, especially research related to pathophysiological developments of diseases. Currently, between 350 to 375 autopsies are performed at JHH every year.

Benefits of autopsies

Autopsies are known for their diagnostic use; however, autopsies not only explain the cause of death, but also provide crucial information for medical quality improvement and scientific discoveries. Autopsies give access to the full analytical view of the patient's condition, often unavailable in our current highly specialized health care system.

The US spends more money on health care than any other country, but has surprisingly high rates of medical errors leading to lower diagnostic accuracy (Doty et al., 2017). According to a report by the Institute of Medicine in 2000, more than 90,000 patients per year die due to medical errors in the US (Kohn et al., 2000). Autopsies allow thorough examination of patients who were critically ill and can provide feedback on the diagnostic and medical decisions. Autopsy can help detect medical error; it provides objective observations and yields clinically significant unexpected diagnoses in roughly 10 to 20% of cases (Sanchez & Chamberlin, 2019). Autopsies are crucial for the improvement of diagnostic accuracy and quality of health care.

Analytical insight obtained from large numbers of autopsies helps identify trends across a broad range of patients and their symptoms. Recognizing pathophysiological and anatomical trends help identify public health hazards and early detection of social epidemics or global

pandemics (Hooper, 2019). Aside from medical significance, autopsies may also help catch signs of bioterrorism or criminal activity (Nolte et al., 2004).

Most important of all, autopsies bring valuable benefits for the patients' families. An autopsy can provide crucial information pertaining to the cause of death, but also can help families discover potential genetic diseases, enabling family members to seek early diagnosis or make considerations for future family planning. Autopsies help bring closure for families, discover important information, and expand medical knowledge.

Future importance of autopsies

With state-of-the-art diagnostic tools and advanced modern medicine, increased diagnostic ability has led to a decrease in demand for autopsies (Goldman, 2018). However, with the COVID-19 pandemic, the importance and the indispensable value of autopsies have once again been brought up to the surface. The disruption caused by COVID-19 made us realize that, despite our advanced modern medicine, we are not prepared for newly emerging infectious diseases, which are predicted to become more common in the future. Autopsies have revealed how the COVID-19 virus can damage the body and helped pathologists and researchers explain how the viral infection can overwhelm the immune system leading to death, including in children (Arnold, 2021). Autopsies will be essential for discovering and understanding new diseases.

Rapid autopsies can provide living cell lines and tissue specimens, used as samples for genetic sequencing and other types of studies. Autopsies continue to be a tool for diagnosis and pathology research, as well as for cutting-edge genetic and molecular research. Through samples obtained from autopsies, researchers were able to find new genes associated with prostate cancer, characterize the pancreatic cancer exome, and profile the human proteome for the first time (Hooper, 2019). Considering the benefits of autopsy and its future importance for patients, families, research, and global health, autopsies should continue to be performed at increasing, rather than declining rates.

2. Problem assessment

Declining autopsy rates and the role of clinicians

Autopsy rates have fallen from 80% in 1955 to 8% in 2018 due in part to the belief that modern medical technology can always provide accurate diagnoses. Dramatic portrayals of autopsies in current media have also increased the general public's misconceptions about autopsy, further lowering the demand. However, autopsies still discover unexpected diagnoses in 10 ~ 20% of cases and the significance of autopsies during COVID-19 has proven that it is still too early to dismiss this valuable medical practice.

The necessity and importance of autopsy findings to the patient's family are acknowledged by clinicians (Hull et al., 2007). However, the clinicians' positive view of autopsy is difficult to convey to patients' families. It is important that clinicians communicate the medical significance and value of autopsy effectively to patients' families. The strength of recommendation for autopsy by the clinician is directly associated with autopsy rates (Burton et al., 2004). The requesting clinician serves as a bridge between the patient, family, and the hospital.

Effective communication correlates to increased autopsy rates

How the clinician approaches the family is a crucial factor in obtaining consent; effective communications by the clinician have been reported to increase autopsy consent rates. According to a study in 2011, 89% of the patients' families gave consent to autopsy when the benefits and values of the autopsy were appropriately presented by the clinician (Tsitsikas et al., 2011). In the same study, 44% of the families voluntarily donated organs for education and research; indicating the families developed a positive view towards medical education and research and that the idea of helping others helped them through a difficult experience. Autopsy rates have been increased from 27% to 69.5% by changing the way clinicians communicated with the families, which shows the importance of relational skills and clinician attitudes (Tsitsikas et al., 2011).

Difficulties asking for autopsy consent

A crucial step of autopsy is obtaining consent. Clinicians should be well prepared to guide family members through the consent process to make an informed decision. Inexperienced clinicians often struggle with this conversation due to insufficient training, general misconceptions about autopsy, lack of familiarity with the consent form (Appendix A), and difficulty showing empathy. Ignoring such struggles may lead to unintentional miscommunication about the autopsy process or the consent form. Pathologists at JHH acknowledge that such miscommunication between clinician and families not only directly affects the autopsy rate, but also results in uninformed consents or void consents from the incorrect next-of-kin. Efforts to correct such mistakes delay the autopsy, affect the quality of the results, and can force the families to revisit a traumatic topic. The problem stems from two main causes: 1) lack of training opportunities for clinicians and 2) lack of educational materials organizing the process of asking for autopsy, currently a ‘verbally narrated experience’.

Lack of training opportunities and educational resources

Frequently, clinicians are required to obtain consent on short notice and in a situation where they are unfamiliar with the patient or family (Finkbeiner et al., 2009). However, there is a lack of training opportunities available to acquaint the clinician with the autopsy procedure and consent, to provide strategies for discussing consent with the legal next-of-kin, and to practice possible scenarios that may arise during the consent process. Individual discussions with Johns Hopkins Hospital (JHH) clinicians revealed a lack of factual knowledge about autopsy such as details about the procedures, possible delays, and effects on funeral viewings (Appendix B). It was also established that prior exposure and early discussion are very helpful for novice clinicians to approach this experience. Multiple studies have revealed that autopsy rates increase substantially after physicians are exposed to formal training in autopsy consent (Sanchez, 2020). Unfortunately, all clinicians interviewed replied that they never received training on asking for autopsy consent.

Another issue clinicians face is the lack of organized educational resources addressing the process of asking for autopsy consent. Asking for autopsy consent tends to be a 'verbally narrated experience', one that is not standardized in clinician training. At JHH, there are occasional in-person simulation seminars hosted by clinicians where interested fellow clinicians have the opportunity to practice difficult conversations such as announcing death. Additionally, medical students at Johns Hopkins School of Medicine take the Transition to Residency and Internship and Preparation for Life or "TRIPL" course during their fourth year, during which they have brief opportunities to learn about the autopsy consenting process. However, neither of these experiences provide holistic, complete training. With COVID-19, even those in-person opportunities have had to shift to virtual group learning and interactive instruction has not been possible.

Creating a less traumatic experience

Autopsy can be a traumatic topic for families whose loved ones have just died, particularly in the case of sudden, unexpected death. Discussing autopsies with families can be extremely stressful for the clinician as well. Many clinicians feel unprepared for this conversation, making the task undesirable and often left to the most junior clinician (Sanchez, 2020). Considering the benefits of autopsy and its role in future medical and scientific development, our goals are: 1) to support clinicians in asking for autopsy consent and 2) for the experience to be less traumatic for the patients' families. Positive experiences of both the clinician and the patient's family are important in creating wider public acceptance of autopsy. To help prepare the clinicians for this difficult conversation, we designed an interactive training module available on multiple devices for efficient learning and training during busy times.

3. Interactive multimedia training and multiplatform accessibility

Organized materials with underlying instructional design created by a medical artist will improve clinician training for obtaining autopsy consent. Prepared clinicians will better inform and

support the next-of-kin during the death of a family member. Conversations will be clearer and more comfortable, resulting in improved transparency, and more fully informed consents for autopsy.

Interactive learning and cognitive theory of multimedia learning

Requesting consent for autopsy is a complex and tricky situation for a clinician. Frequently, the clinician did not know the deceased patient and this is the first time the clinician is meeting the family. Not only does the clinician need to deliver information clearly, but he or she needs to be considerate, clinically empathetic, and a good listener. To help train clinicians to conduct and facilitate a highly complex and emotional conversation, interactive and cognitive multimedia learning methods were used in the design of this resource.

Interaction is one of the most important learning components both in classroom-based traditional and web-based distant education (Jung, 2002). Unlike passive learning, where the information is delivered and learners intake and retain information through memorization, interactive learning enables learners to participate in the questioning and learning process. Through use of the ‘choose your own adventure’ format, the training module creates a meaningful interaction, helping clinicians efficiently remember the content of the training.

Learning experiences can be greatly enhanced through experiences combining multiple sensory components (Mayer, 2020). Through the use of narrative audio, relatable visual imagery, and feedback in text, we reinforce the cognitive learning experience. Instead of passively remembering talking points for a conversation, the clinicians will relate to the subject matter through storytelling. While working on the problems presented throughout the training module, clinicians will build on previous experiences and explore how to make better choices based on feedback from previous questions.

Online learning and multiplatform accessibility

It is common for a clinician to have not received training in asking for autopsy consent prior to their residency. Even during their residency, the only related experience may be the rare opportunities to observe other clinicians requesting consent. In interviews, clinicians mentioned that they would have benefitted from training beforehand. Now, due to COVID-19, training opportunities at the Johns Hopkins Hospital are further limited. This is why a multiplatform online training module accessible on multiple devices is needed. Clinicians are busy and active; for a training module to be efficient and effective, it should be accessible regardless of the location, platform, or device used.

4. Project objective

Our mission is to improve the experience of autopsy consenting by converting the learning experience - typically observing an intense conversation of requesting autopsy consent from a grieving family member - into an easily accessible online training resource. We designed a multi-OS, mobile compatible, electronic tool featuring visual resources for clinicians. The project focused on three components: 1) a training module webpage, 2) a quick reference mobile app, and 3) a hand-held pocket guide.

Training module webpage

The training module webpage will provide comprehensive factual knowledge about autopsy, emphasize empathy and sensitivity, and teach clinicians the process to obtain a correctly completed consent form. The aim is to simulate the in-person experience as closely as possible in an online space through the use of interactive multimedia. The webpage will provide descriptions and advice for each step of the conversation that will take place when asking for an autopsy consent. The clinicians will be able to look up frequently asked questions and solutions to sensitive situations.

Quick reference mobile app

The quick reference mobile app will reinforce the key points taught in the training module, quickly and efficiently. It is designed for use by the clinician just prior to approaching the family to ask for autopsy consent. The mobile app contains important information distilled from the training module website and last-minute tips for the conversation. The app may also be used to quickly look up information during the request for consent dialogue. The aim is to provide a quickly accessible reference and to help the clinician mentally prepare for this challenging conversation.

Pocket guide

The pocket guide is a small hand-held, printed booklet including a check list and supporting visuals for the family during the conversation. The checklist will help clinicians make sure they have checked and obtained all of the correct necessary information. Supporting images include diagrammatic illustrations to visually help the clinician answer questions asked by the family. The aim is to provide non-digital visual resources that will not disturb the conversation or seem disrespectful to the family.

5. Intended audience

The resource designed will allow the clinical audience to gain familiarity with autopsy consenting through interactive media, clinical scenario simulations, and well organized, accessible information. Future developments include feedback from the audience, which will help assess the frequency of use and effectiveness of each component of the tool: training module, quick reference, and pocket guide.

Practicing clinicians

Clinicians can learn in advance using the training module website, then utilize the quick reference and pocket guide when unexpectedly called upon to obtain an autopsy consent. Novice clinicians will gain awareness of required knowledge and considerations to better prepare

themselves before interacting with the patient's family. Experienced clinicians and autopsy practitioners can use this resource to supplement their current routine and support training activities.

Medical students

The tools designed for this thesis may also be incorporated into medical education at the Johns Hopkins University School of Medicine. First exposure to the tool can be just prior to clinical rotations, incorporated into the 'Transition to Residency and Internship and Preparation for Life (TRIPLE)' course. The use of the resources will help medical students be better prepare for the difficult conversation that may happen unexpectedly during their residency.

Patient families

Supporting illustrations may be shared with families to clarify consent options during the conversation. The pocket guide will visually help the family, who may be having difficulty processing information while grieving. This will not only improve the experience for the clinician, but also create a less traumatic experience for the family, leading to better informed consents.

MATERIALS AND METHODS

1. Needs assessment

Individual discussions with clinicians at Johns Hopkins Hospital (JHH), with experience requesting autopsy consent, provided an important opportunity to better understand the needs of the audience for whom this resource was developed. Informal discussions were held with 12 clinicians using a needs assessment questionnaire (Appendix B) as a guide. Based on these discussions, it was determined that a training module would be useful for medical students, novice clinicians, and even experienced clinicians when preparing, on short notice, for this difficult and emotional conversation. Novice clinicians often lack training and are unprepared to ask for autopsy consent from a grieving family.

The project was initially conceived in a webpage format. However, upon discussing with the clinicians, we realized the need for not only a training module webpage, providing details about autopsy consenting, but also a quick reference mobile app, enabling easy and quick access to important information. There was also exploration of the need for simple illustrations, which will help the families visually understand and retain information related to the consent. These illustrations are combined and organized as a pocket guide.

2. Training module

Content selection

The web-based training module was designed to provide detailed explanation about autopsy and the autopsy consenting process. The information presented in the training module is intended for learning before a clinician's first autopsy consent conversation takes place. The contents are organized in way to ease the clinicians into the topic, starting with background information, important details to check, and factors to consider before, during, and after the conversation (Tables 1, 2).

Training module The training module webpage will provide factual knowledge, emphasize empathy and sensitivity, and teach clinicians the process to obtain a correctly completed consent form.		
Background	1. Introduction to autopsy	- Brief intro to autopsy (post-mortem examination) - Decrease in recent autopsy rates - Clinician attitude and autopsy consent rates
	2. Struggles of asking for consent	- Lack of exposure to training opportunities - Lack of educational materials - Difficulty in cultivating clinical empathy
	3. Consent form review	- What is a post-mortem examination? - How can the post mortem examination help? - Who pays for the autopsy? - Will this affect the funeral? - Who can sigh the consent form? - Can specific requests be made? - How is the body returned after the autopsy? - When will the final results come out? - Who to contact to learn mor e?
	4. Check list	- Correct signator - Dates and times - Spellings and birth dates - Restrictions are clear and make sense - Disposition is valid - Body ID is correct - Does ME need to be called?

Table 1. Training module: Background

Training module The training module webpage will provide factual knowledge, emphasize empathy and sensitivity, and teach clinicians the process to obtain a correctly completed consent form.		
Before conversation	1. Review charts and discuss with the nurse to check who is present for the decedent.	
	2. Consult with attending for questions.	
During conversation	1. Best practices	- Right timing and compassion - Special medical cases - Experienced clinician - Honesty and belief in the benefits of autopsy - Good interaction with patients and family
	2. Challenges and poor practices	- Bad timing and rush - Severed communication - Emotional family - Uncertainty regarding religious restrictions - Negative image of autopsy - Bad interaction with patient's family
	3. Frequently asked questions	- Effects on funeral - Autopsy process - Cultural or religious issues - Grief and bereavement - Receiving autopsy results
	4. How to approach the family	- Parent consenting for young child - Parent consenting for adult child - Adult child consenting for parent - Spousal consent - Expected vs Unexpected death
	5. Wording your request	- Show compassion - Address their worries and offer help - Use friendly and warm words - Normalize your requesting routine
	6. Language to avoid	- Words with negative connotations - Unnecessary details - Sound uncertain - Being aggressive instead of suggestive
	7. Interacting with the family	- Show respect and courtesy - Introduce yourself - Ease into the autopsy - Give the family time to process - Be available - Show appreciation for their help
After conversation	1. Efforts made by the clinician	- Let residents observe when requesting consent - Suggest courses for med school - Attend simulation workshops

Table 2. Training module: Before, during, and after the conversation

Interactive simulation

The simulation is designed to cover the majority of topics clinicians may experience, and should be able to explain to the family, during the consent conversation (Figure 1, Appendix C). This includes: initiating the conversation, discussing aspects of the autopsy with the family, answering their questions, and hearing the family's final decision.

An interactive 'choose your own adventure' format was chosen for the autopsy consent simulation. The simulation is organized into three large branches depending on the clinician's approach and responses to the family: a *great* approach, a *neutral* approach, and a *poor* approach (Figure 2).

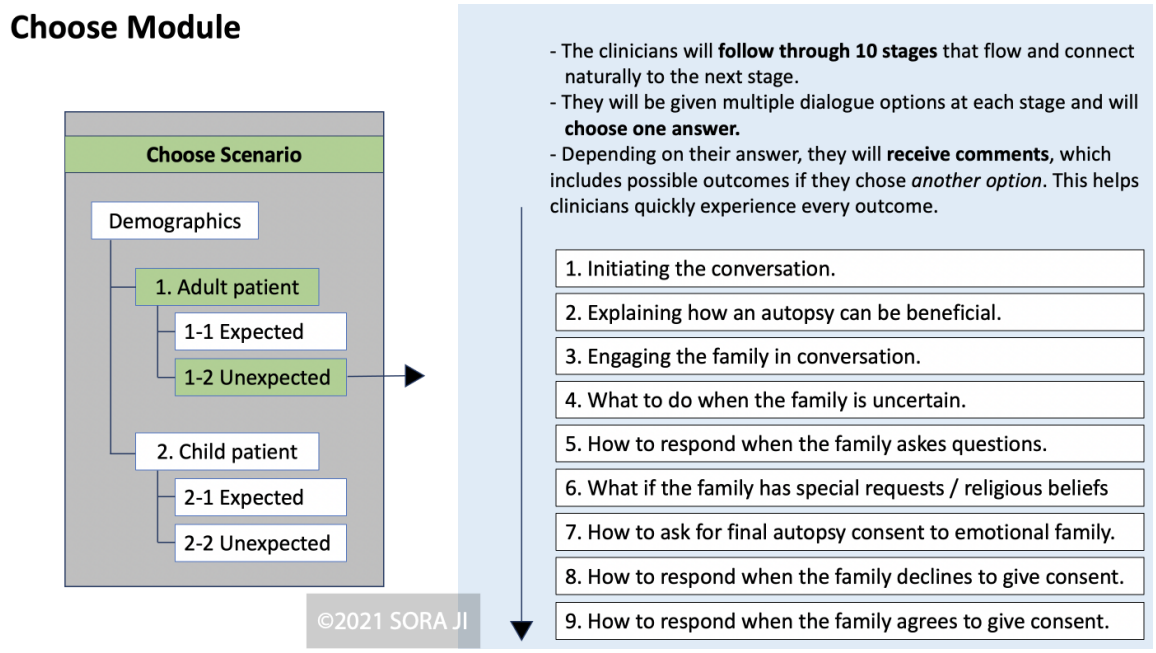


Figure 1. Contents of the interactive simulation.

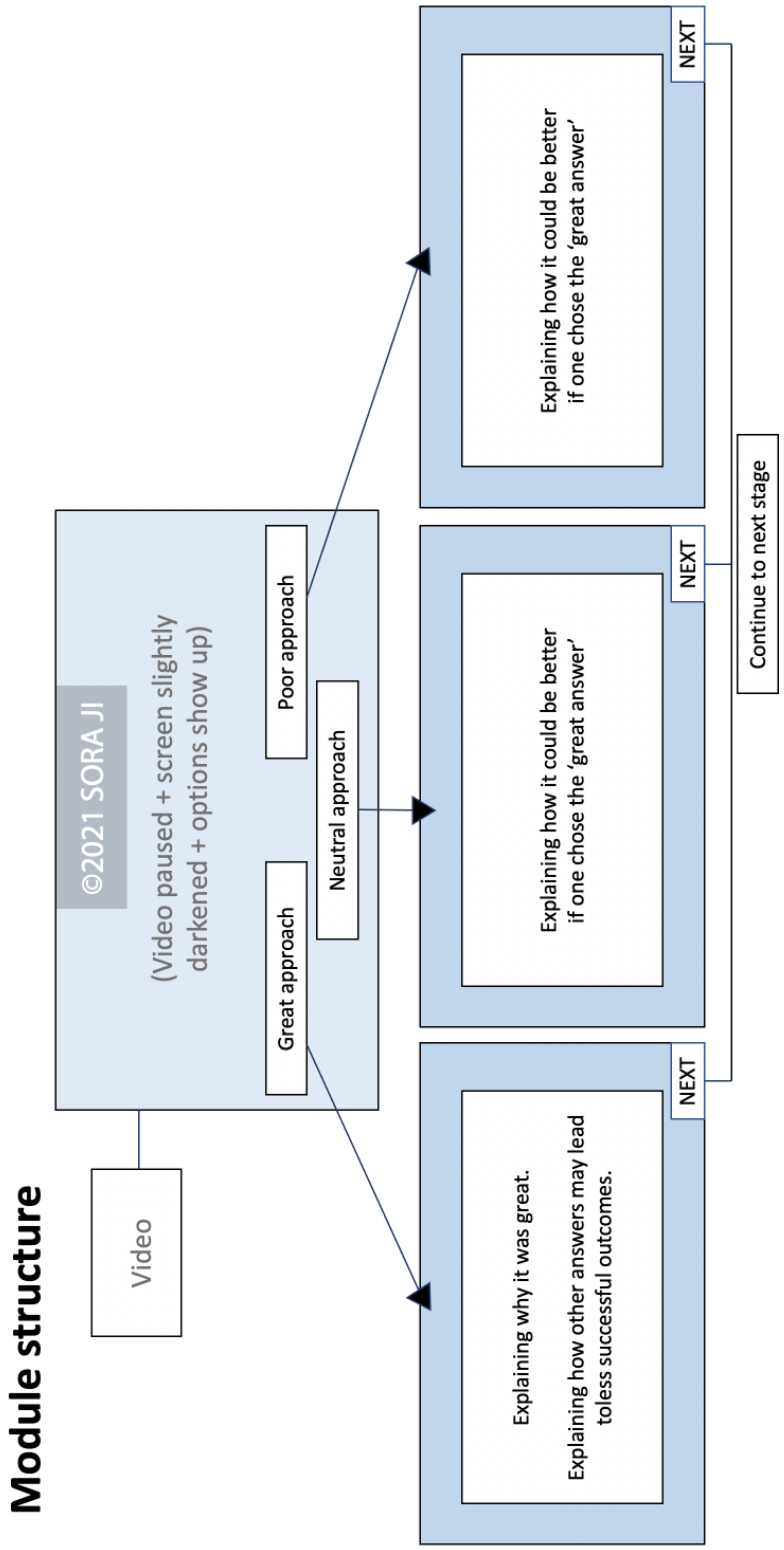


Figure 2. Three branches of the interactive simulation: *Great* approach, *neutral* approach, and *poor* approach.

As described in Figure 2, there are pauses during the simulations where the user has to decide how to react, as the clinician, to certain situations in the conversation. The screen goes dark and a question pops up on the screen. Three options (multiple choice) are presented. After the user chooses their answer, they observe a live action segment of the clinician delivering their selected response. The story continues with the patient's family responding to the chosen answer. The order of which the three answer options (good, neutral, and poor approach) show up on the screen is randomized for each question (Figure 3). At the end of each segment, the user receives feedback explaining either what was good or bad about their chosen answer. Among the three structural options for feedback as shown in (Figure 4), we used Option 2, providing individual feedback for each step, instead of providing a single complied feedback at the end of the simulated conversation.

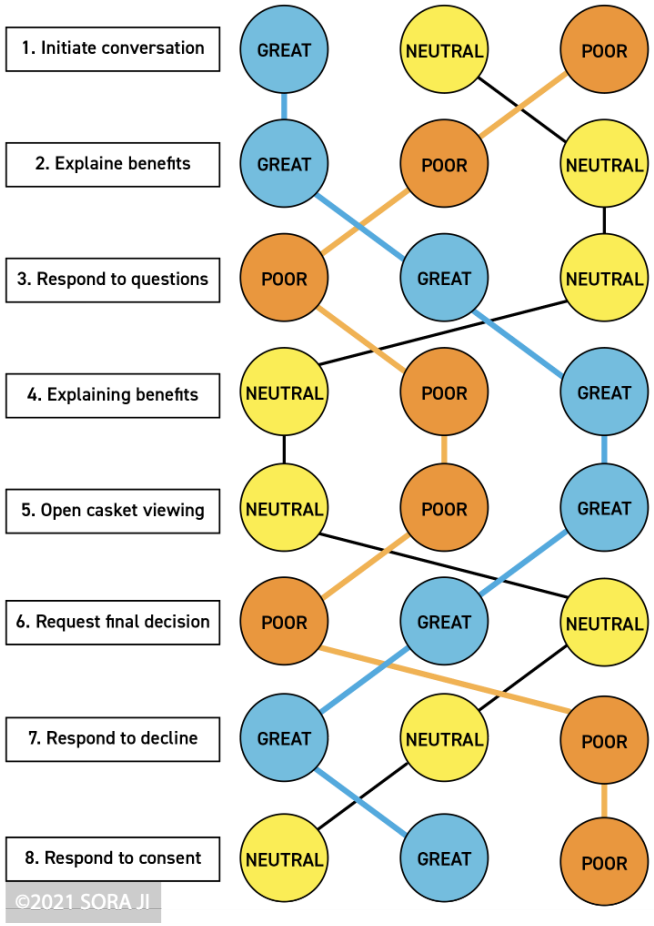


Figure 3. Randomization of the answers for each of the 8 steps in the conversation.

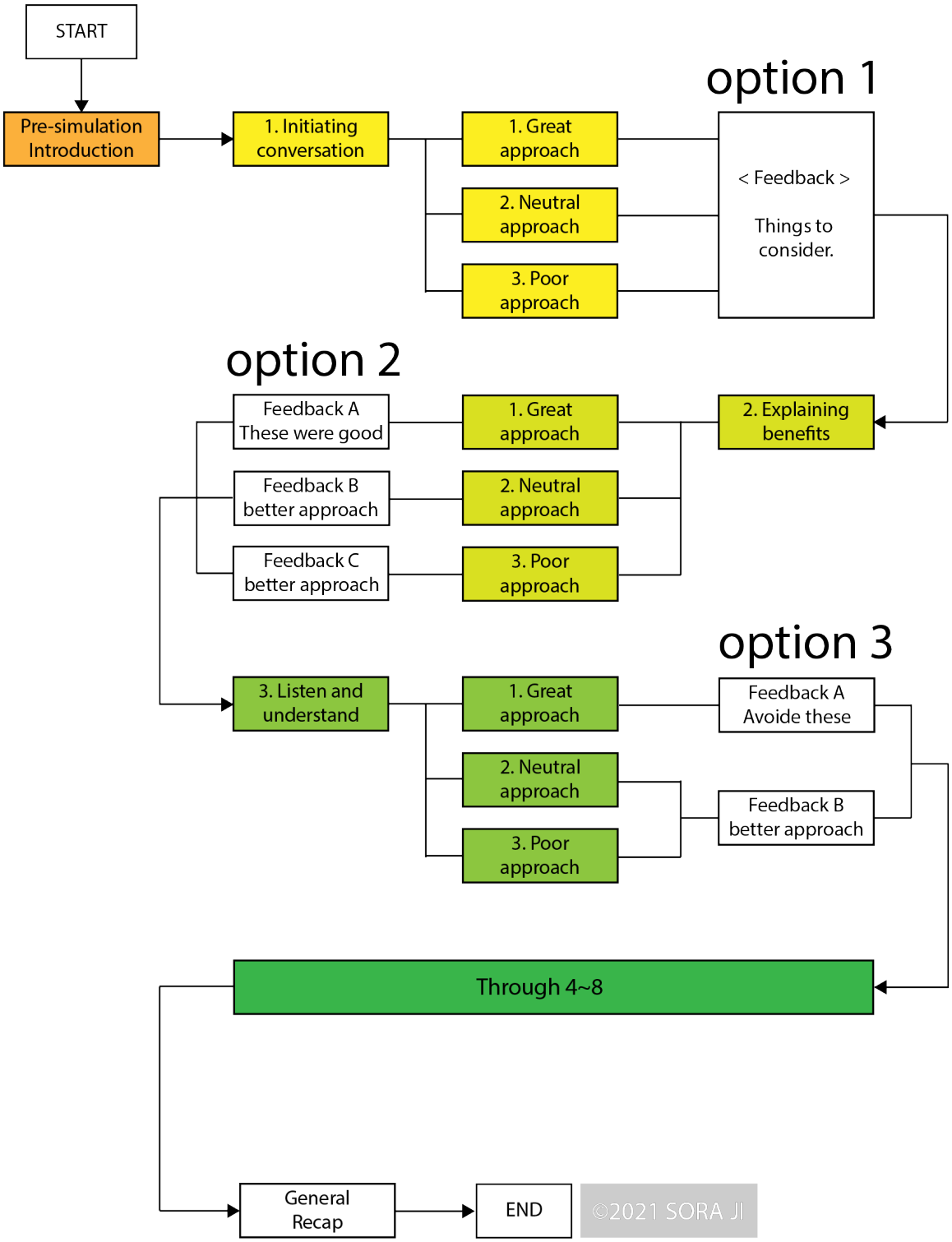


Figure 4. Three different feedback options for interactive simulation.

Through the use of interactive media, in which the learner participates in the decision-making process, the learning experience is designed to be more meaningful, leading to better retention of the subject matter. The simulation is intended to recreate experiences as closely as possible to what the clinician may experience in a real-life consent conversation.

a. Media selection: live action recording

Initially, the simulation was developed to be a 2D interactive animation, and storyboards were created (Figure 5). However, clinicians suggested a live action recording will capture more of the subtle realistic aspects of a personal interaction than a 2D animation, making it easier to relate to and empathize with, and learn from. This feedback led to the exploration of recording live action role play using a Standardized Patient and a JHH clinician. Standardized Patients are individuals trained to play the role of patients in the training of medical students and other healthcare providers. The storyboards, though ultimately not used for animations, provided a useful framework to capture the challenges and emotions to be represented in the autopsy consent conversation recorded with live actors.

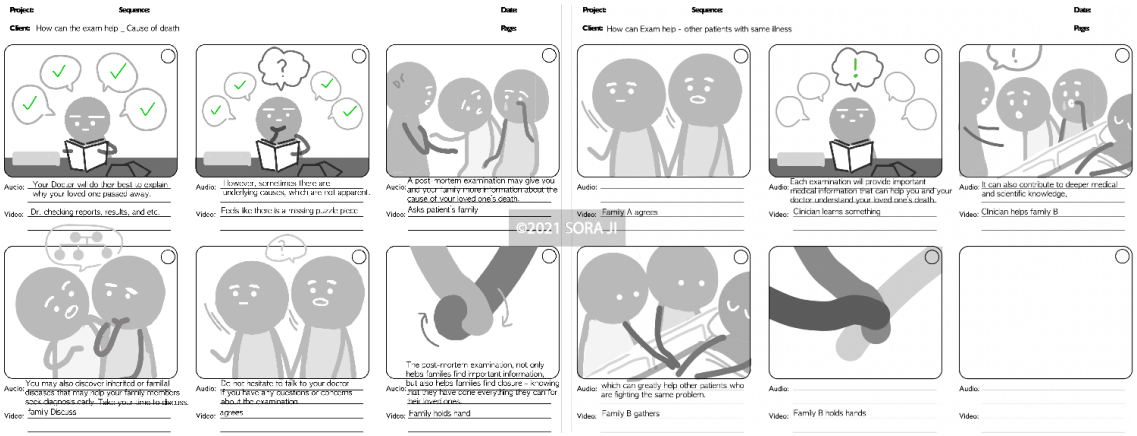


Figure 5. Sample of rough storyboard for 2D animation. *Text not meant to be read.*

b. Script and narration

The content for the script and narration used in the live action simulation was based on the content designed for the training module webpage. The aim was to highlight the impact of

conveying appropriate sympathy and to include important factual knowledge in the dialogue. The script was reviewed by a pathologist and clinician at JHH for accuracy and flow (Appendix D).

For the role of the clinician, emphasis was given to clinical empathy, delivered in forms of word choice, response, and level of consideration. For the role of the family member, emphasis was given to emotions of grief, delivered in forms of confused dialogue, anguished facial expressions, and “closed” body language. Through realistic background setting and character design, the goal was to ensure a natural, authentic dialogue (Appendix D).

Narrations inserted into the flow of the live action consent conversation simulation further help the audience contextualize and reinforce the main concepts, provide additional information, and address situations not encountered during the role play. The script for the narrations was reviewed and recorded by a pathologist at JHH. Both the narrations and the script are subtitled to expand accessibility and usability for all learners (Appendix E).

c. Pre-simulation introduction

Because the simulation starts with initiating the conversation with the family, a short checkup segment, prior to the simulation, was developed to remind the clinician of the steps and precautions to take before entering the room (Figure 6). The pre-simulation introduction is presented in a ‘question and answer’ format. Three different situations are presented; the clinician selects the answer (review the chart, talk to the nurse, or look up the phone number) by clicking on a simplified icon representing the response they would select. (Figures 6 - 8).

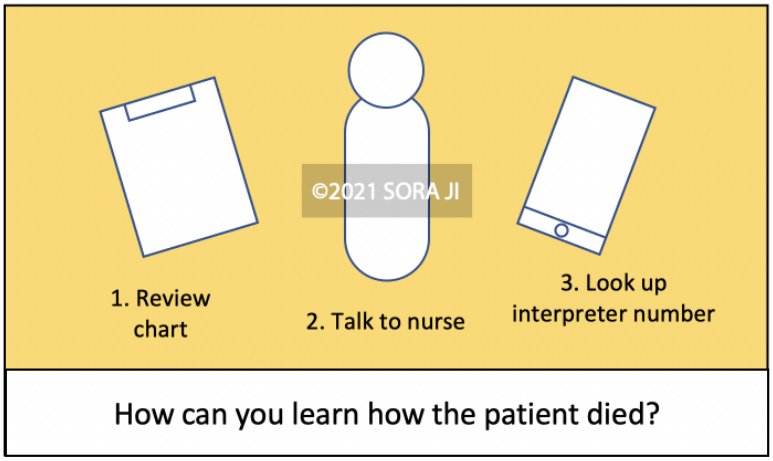


Figure 6. Schematic for pre-simulation introduction.

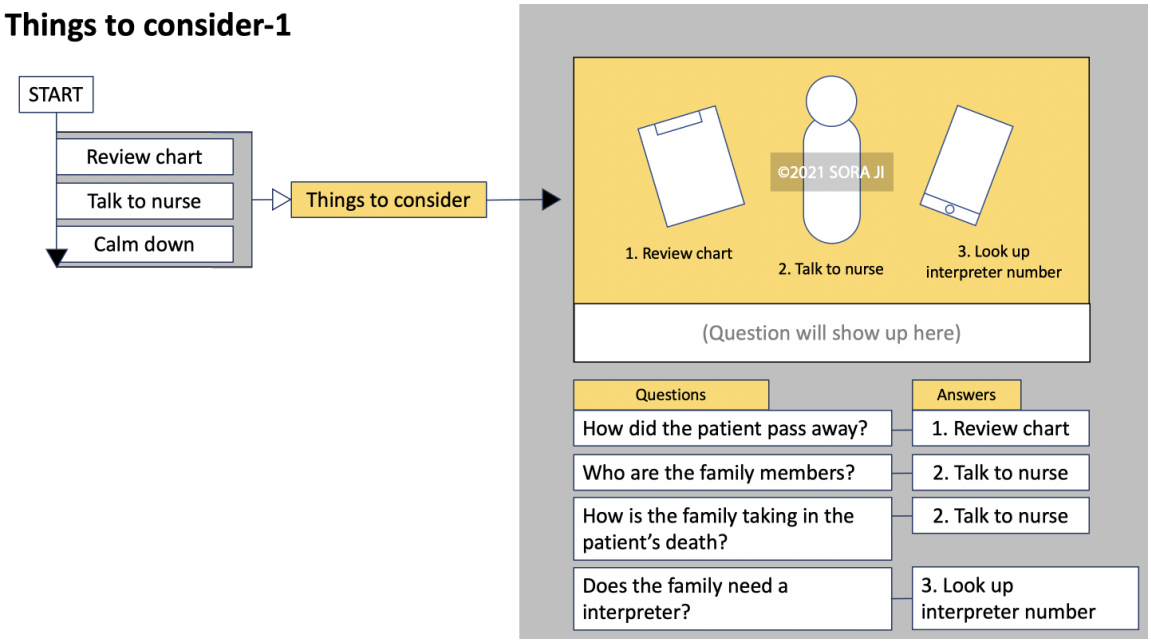


Figure 7. Flow chart for pre-simulation introduction. *Not all text is meant to be read.*

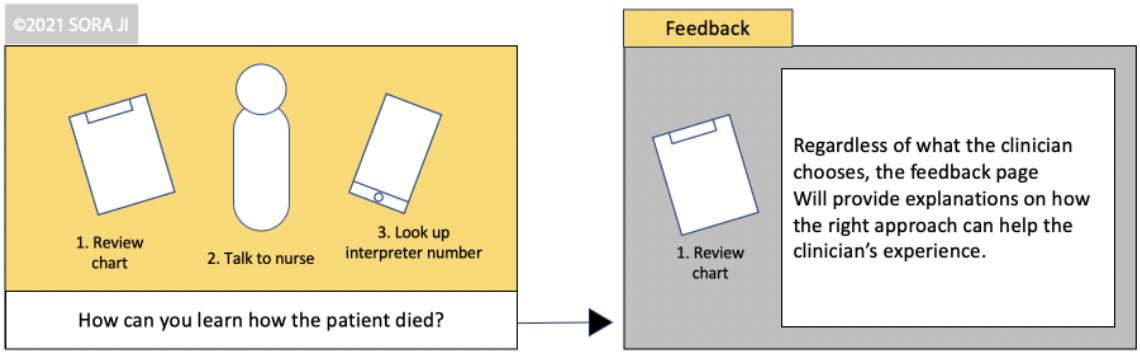


Figure 8. Feedback for answers during pre-simulation introduction. *Not all Text meant to be read.*

Live action recording using Standardized Patients

Standardized Patients (SPs) are professionals, often with acting experience, who are provided scripts and trained to portray patients during the acquisition and assessment of clinical skills of medical students, residents and other healthcare professionals. SPs are important resources for educational simulations and are widely utilized during in-person training at the JHH. This is the first instance of using SPs to create educational material combined with medical art at the Johns Hopkins School of Medicine, in the Department of Art as Applied to Medicine. This opportunity has shed light on the effectiveness of SPs and their potential in helping create future medical communication projects.

a. Recruiting standardized patient (SP) and clinician for role play

One SP was selected to role play the patient's family member; a retired Hopkins clinician with SP experience was recruited to role play the clinician asking for autopsy consent. In order to recruit the SP, the JHH Simulation Center was contacted and a project description with specifications for the role was submitted (Appendix F). Brief, online interviews were conducted to provide further information about the role and audition the SP candidates (Appendix G). After the interviews, one SP was selected for the "patient's spouse" role. The clinician role was played by

the former JHH pediatrician who helped us review the script, and is an expert in “breaking bad news” in the medical setting.

b. COVID-19 precautions

COVID-19 precautions were taken to ensure the safety of all participants during the filming. Everyone wore masks and the SP and clinician sat further away than in a normal, pre-COVID-19 autopsy consent conversation. This distancing may have limited the amount of information presented through facial expression, tone of speech, body language, and physical touch in a non-COVID-19 setting. However, it provided an important opportunity to show how the autopsy consenting conversation may occur during global pandemics, including COVID-19.

c. Filming

To recreate an office setting at a hospital, the filming took place in the library of the Department of Art as Applied to Medicine. The library is a spacious open setting, providing sufficient airflow. The SP and clinician sat facing each other, but further away than usual due to COVID-19. A coffee table was positioned between the clinician and SP. A white coat, stethoscope, clipboard with printed out consent form and a pen, box of tissue, and cup of water were prepared as props. A lavalier microphone was taped underneath the coffee table to catch the dialogue while still remaining unseen. Three cameras were used for the recording process. Camera 1 was positioned behind the clinician to provide an over-the-shoulder shot of the SP. A second camera recorded the wide view of both the clinician and SP from a distance, Camera 2. The third camera, Camera 3, was positioned behind the SP and provided an over-the-shoulder shot of the clinician (Figures 9, 10).

Figure 9. Photo of location for filming.

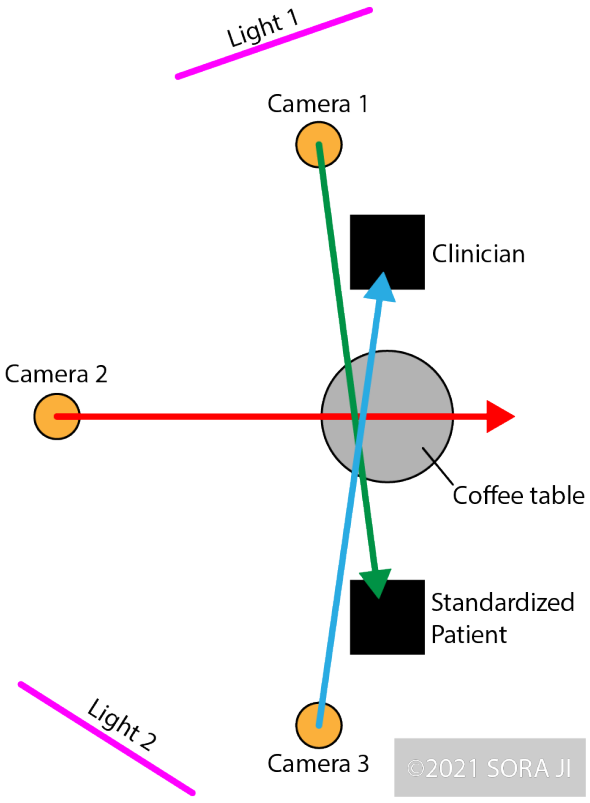


Figure 10. Schematic of the three-camera set up.

Over-the-shoulder shots were used to overcome the distance between the clinician and SP; by including both subjects in the frame, it reinforces the impression that the two subjects are engaged in the conversation. Three versions of the consent conversation were recorded; the clinician depicted and ideal or “great” approach to the conversation; a “neutral” approach and finally a “poor” approach and interaction with the patient’s family. The recording took approximately two hours; the SPs were compensated. Still photos were taken to capture key moments in the conversation, and for reference for still images.

The raw recordings were edited using Adobe Premiere Pro and Adobe After Effects. Emphasis was given to subtle facial expression and body language of both the clinician and SP. The still photos were edited using Adobe Lightroom. Specifics for all devices and programs used during the recording and editing process are listed below (Table 3).

Camera	• 1 x Canon EOS Rebel T7i (DSLR) + 18-55mm IS STM Lens • 2 x Canon PowerShot G7 X Mark II
Microphone	• BOYA BY-M1 Lavalier Microphone

Table 3. Devices used for filming.

To observe COVID-19 precautions and to prevent echoing, we filmed in a medium sized library room with lots of books and shelf items. We were concerned that the busy background would attract the viewer’s attention and that the cameras were having a harder time focusing on the subject. The quality of acting is impactful enough to grab the viewer’s attention back to the conversation. However, for future attempts and updates, it would be best to film at a location with fewer items in the background.

The audio was slightly muffled not only due to masks, but also because the mic was attached to the coffee table, which was far from the clinician and SP. This was also due to the fact that only one out of the three cameras used had a mic input source, which forced us to use

one mic to record both subjects. For future attempts, it would be best to use at least two cameras with mic input sources and use individual mics for each subject. This will improve the sound quality.

With only one tripod available, we experienced limitations with the height and angle of the recordings. We had to balance the other two cameras on a shelf and a stack of books. These surfaces did not provide stable support, so after pressing the record button, we had to wait until the cameras stopped shaking. For future attempts, it would be best to obtain more tripods when shooting with multiple cameras.

Creating interactive media

'Camtasia' software was used to create an interactive simulation. The recordings edited in Adobe Premier were imported into Camtasia (Figure 11). The 'choose your own adventure' interactive format was achieved through using callouts and interactive hotspots (Figure 12). The questions and the answer choices were added onto the clip as readable texts using the callout feature. Each callout was treated like an individual button, that jumps to the corresponding responses within the clip, when clicked on. The responses were marked within Camtasia with markers, which provided a hotspot link to achieve this interactive feature (Figure 13).

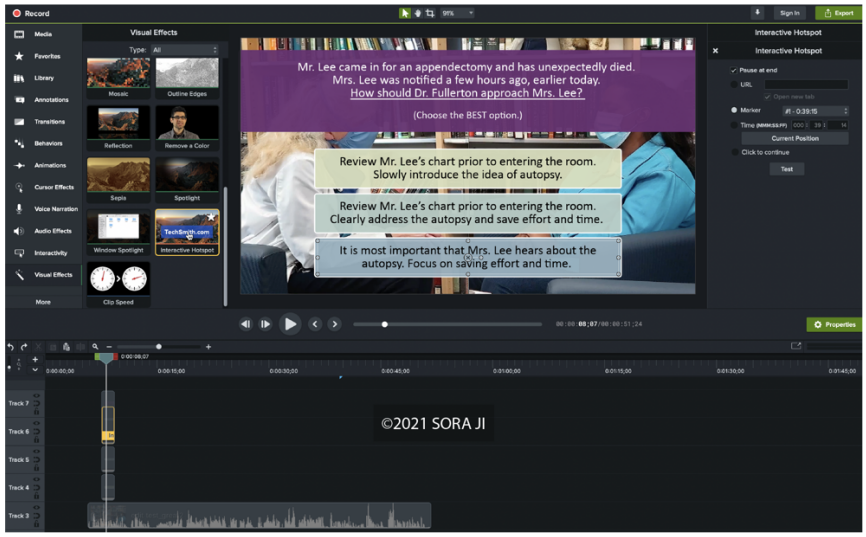


Figure 11. Edited recording imported into Camtasia. *Text not meant to be read.*

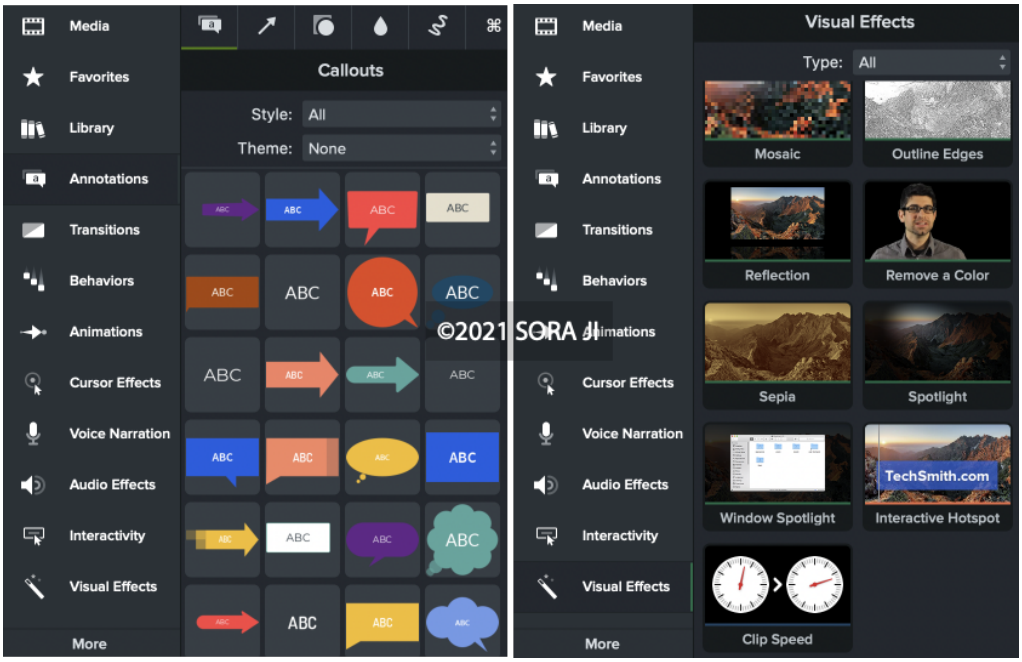


Figure 12. Features used in Camtasia. *Text not meant to be read.*
(Left: Callouts, Right: Interactive Hotspots)

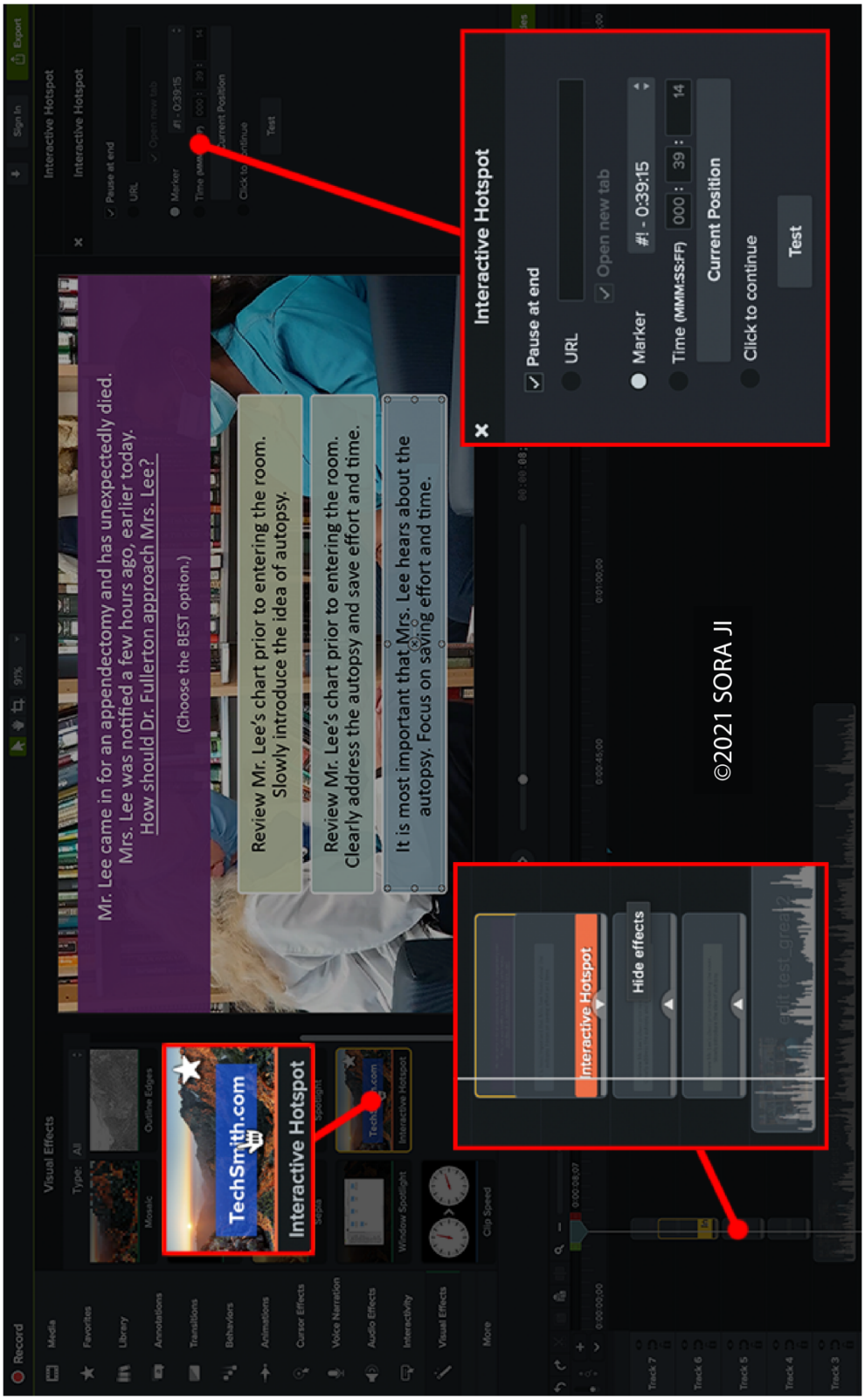


Figure 13. Using Interactive Hotspots.

Prototype webpage

The prototype of the training module webpage was built with Adobe XD. The design elements used to provide structure and visual support for the training module webpage were created using Adobe Photoshop and Adobe Illustrator. Attention was given to the mood and atmosphere of the webpage, which influenced the choice of color, shape, and image. Some key words when considering the mood were usable, gentle, professional, and respectful. Contents of the webpage were selected upon consultation with a JHH pathologist. Emphasis was given to easy navigation and access to materials. A flow chart (Figure 16) and low fidelity wireframes (Figures 14, 15) were created to convey these interactive design concepts.

a. Wireframes

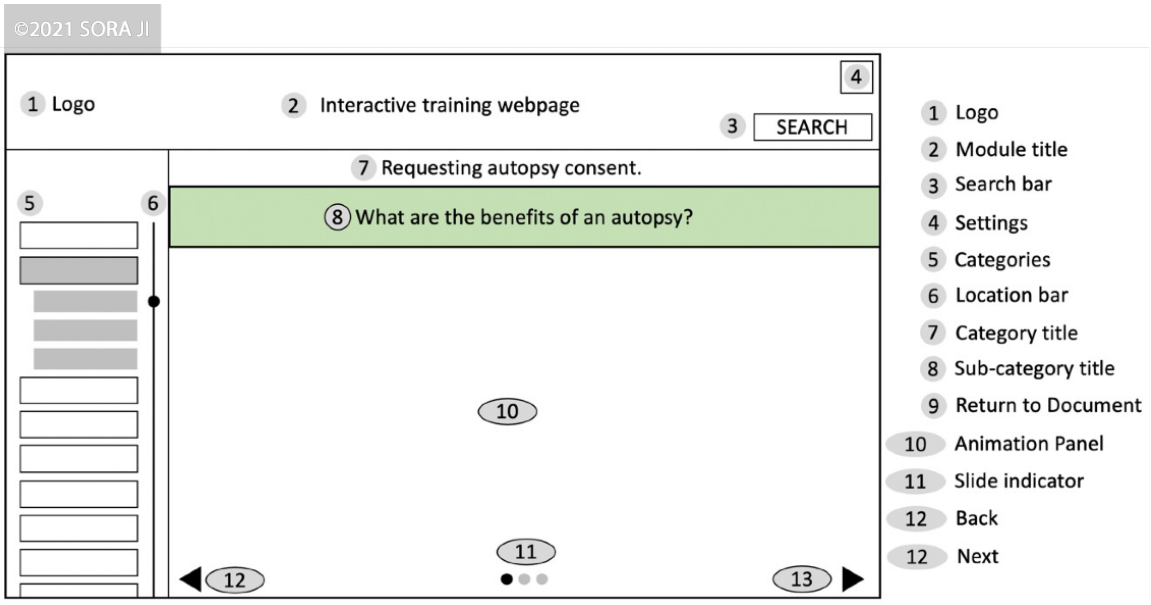


Figure 14. Low fidelity wireframe for training module webpage.

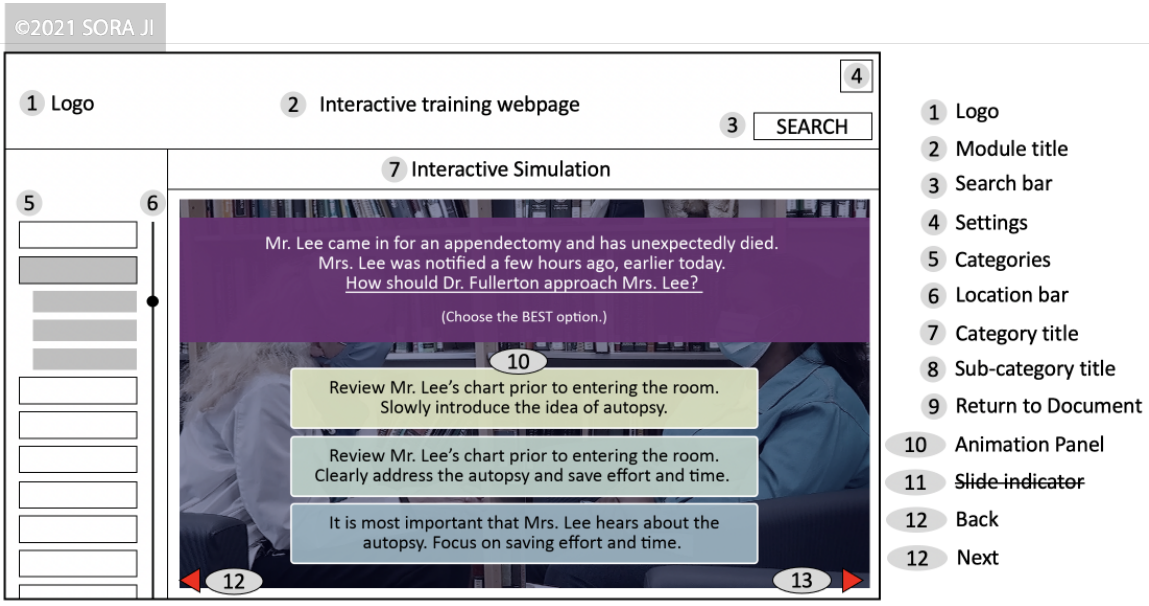


Figure 15. Interactive simulation placed within low fidelity webpage. *Not all text meant to be read.*

b. Flowchart for webpage.

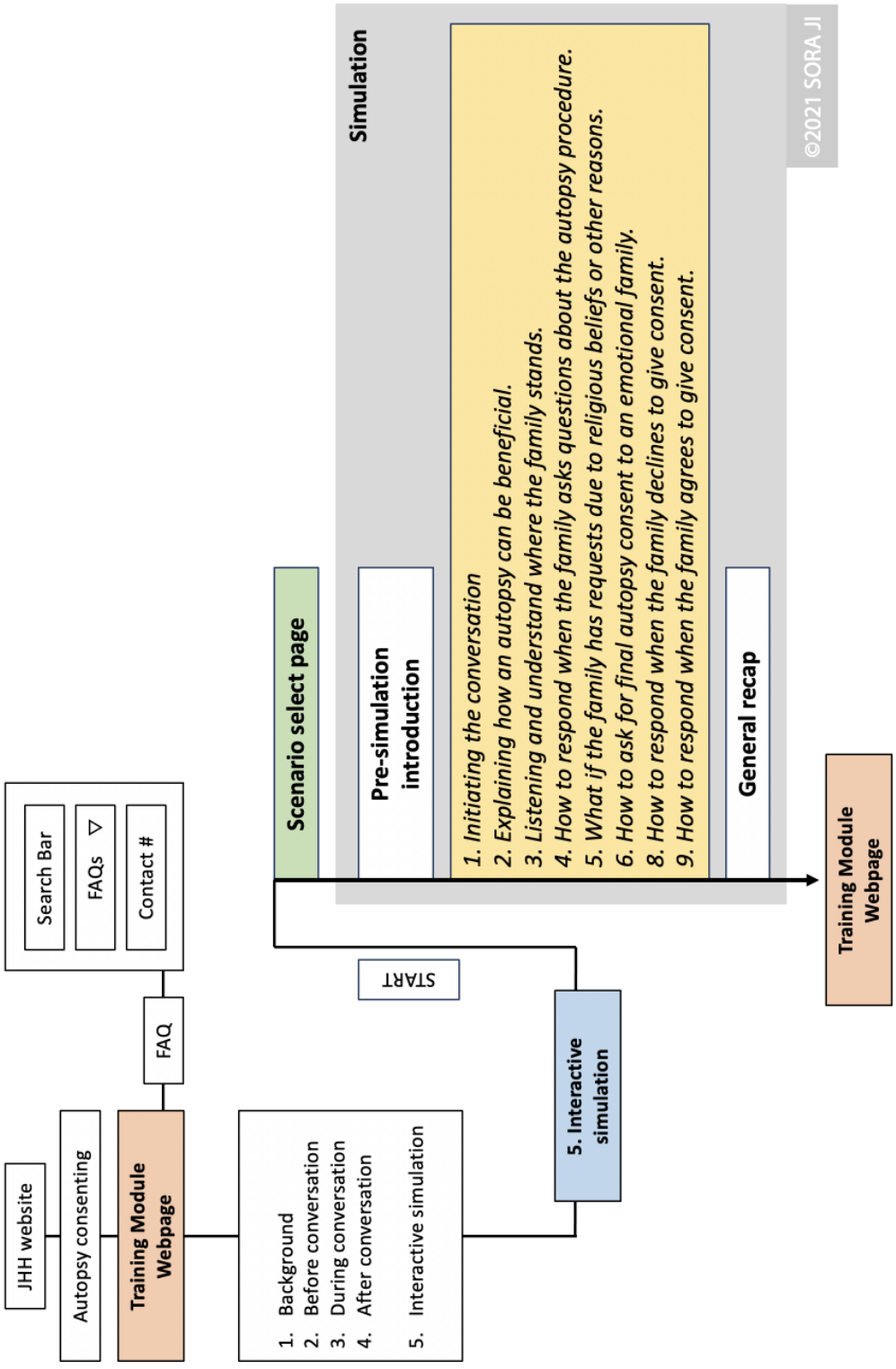


Figure 16. Flow chart for access to interactive simulation.

3. Quick Reference mobile app

Information distillation and content selection

The quick reference app is the second component of the autopsy consent training material; it provides easy access to key information for the consent conversation. For maximum efficiency, information was distilled from the training module webpage, leaving only the absolute necessary details needed when asking for an autopsy consent. Advice from experienced clinicians obtained during the individual discussions was organized and added to the content of the quick reference (Table 4). When reviewed just prior to entering the room, the tips and check points on the quick reference app will help clinicians prepare themselves when asking for autopsy consent.

Quick Reference The quick reference application will reinforce materials taught in the training module in a quick and efficient way. It is designed for use just prior to the consent conversation.	
Consent checklist	- Correct signator - Dates and times - Spellings and birth dates - Restrictions are clear and make sense - Disposition is valid - Body ID is correct - Does ME need to be called?
Contacts	- Admitting office - Interpreter service - Religious service - Pathology department - Legal office - Others
Tips	- Ask for help when uncertain - Review patient chart - Give the family time and space - Stay calm - Avoid scientific or medical jargon - Ease into the autopsy - Be patient and don't rush - Listen and read the room
Resources	- *Illustration 1: Order of legal next-of-kin in Maryland.* - *Illustration 2: Open casket viewing.* - *Illustration 3: Next steps to prepare.*

Table 4. Contents for Quick Reference mobile app.

Format selection

We chose a mobile app as the format for the quick reference. The quick reference is intended to provide easily accessible information right before beginning the dialogue. If a clinician needs to consult the app during the conversation, they should do so only after asking permission of the family member. A mobile app enables quick and easy access to information without restricting the location of the clinician.

Prototype app

With the distilled information, a flow chart was created to design the structure of the prototype app (Figure 17). The wireframes for the prototype app were built with Adobe XD and the visual elements were created using Adobe Illustrator (Figures 18 - 22). The mobile app is designed for a smartphone, but may be available on tablets during future development. Colors with sufficient contrast, and font sizes to ensure accessibility and usability, will be considered in later iterations of design.

a. Flow chart

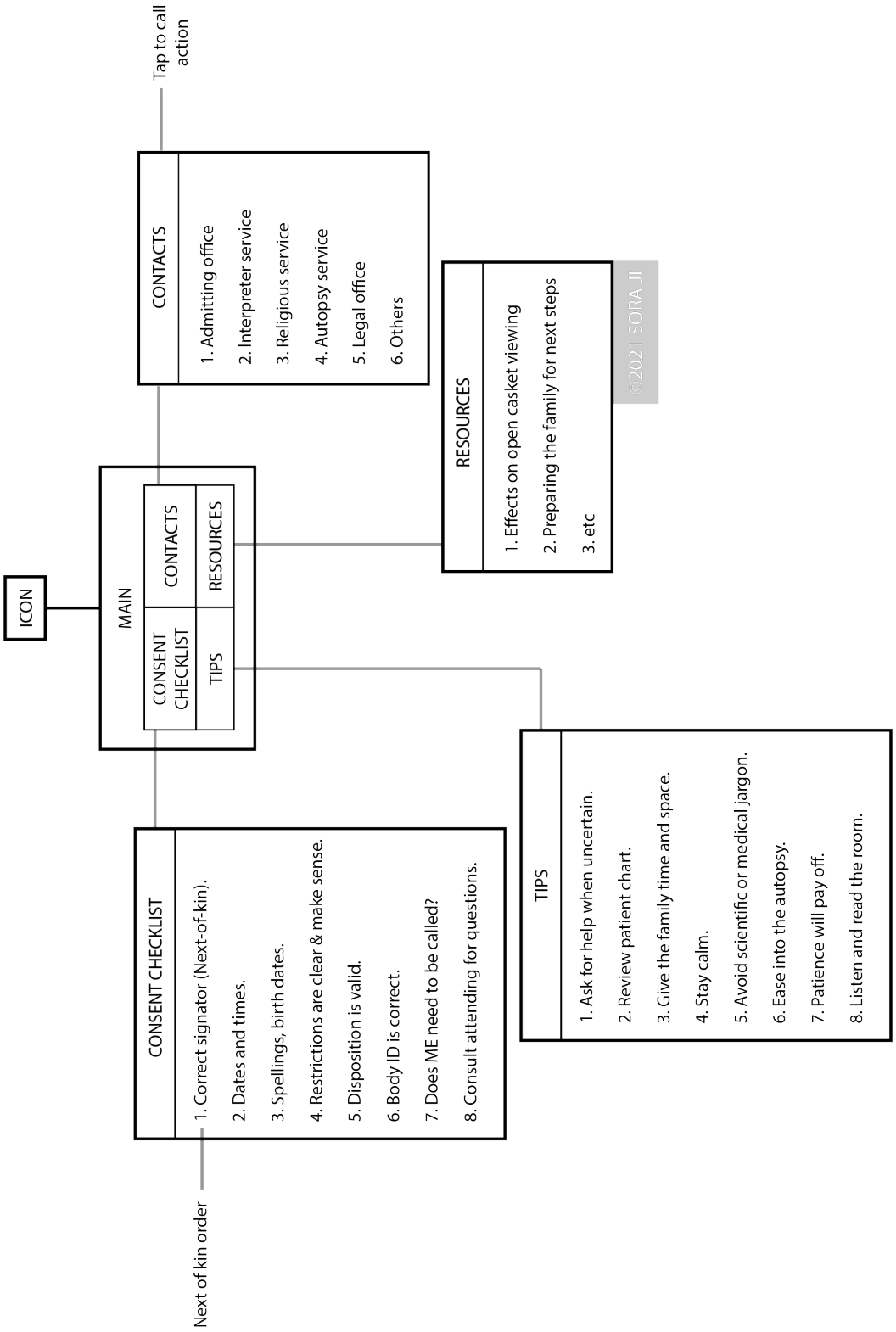


Figure 17. Flow chart for Quick Reference mobile app.

b. Wireframes

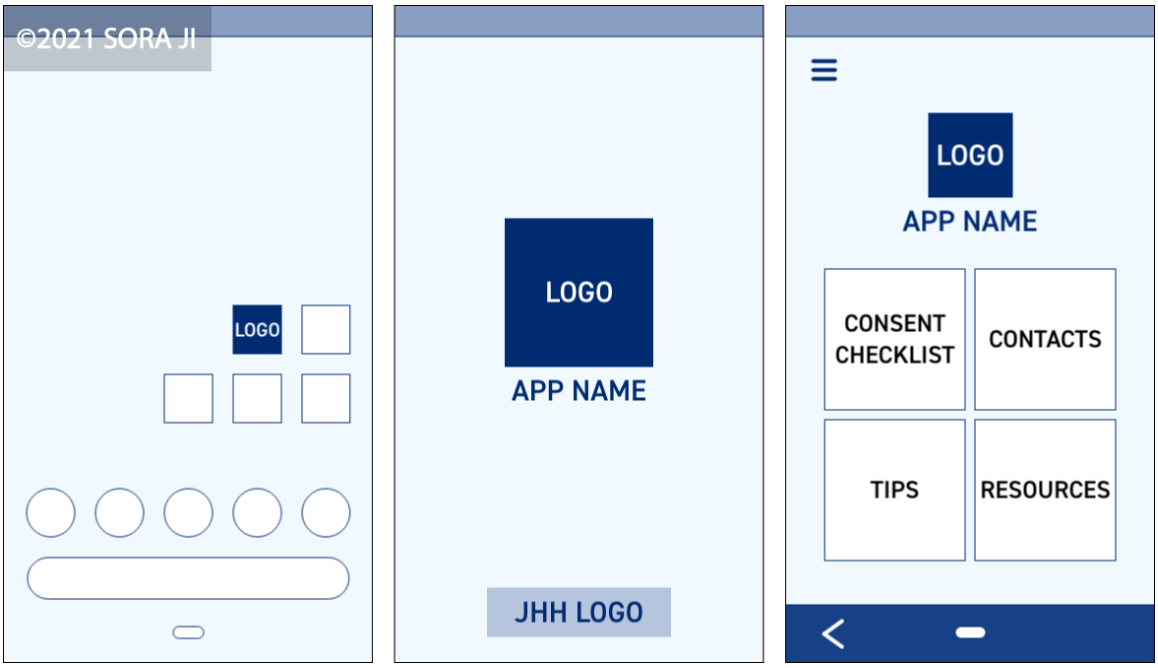


Figure 18. Layout for app launch. (Left: icon, Middle: start-up page, Right: main page)

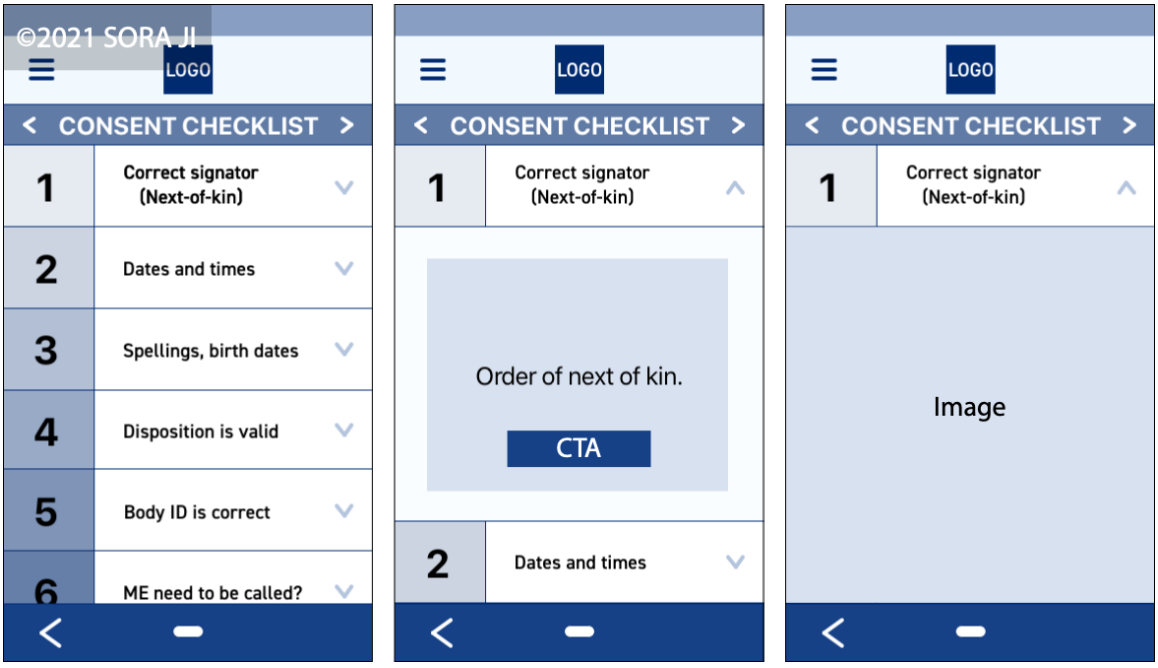


Figure 19. Layout for consent checklist. *Not all Text meant to be read.*
(Left: main page, Middle: individual content page, Right: resource page)

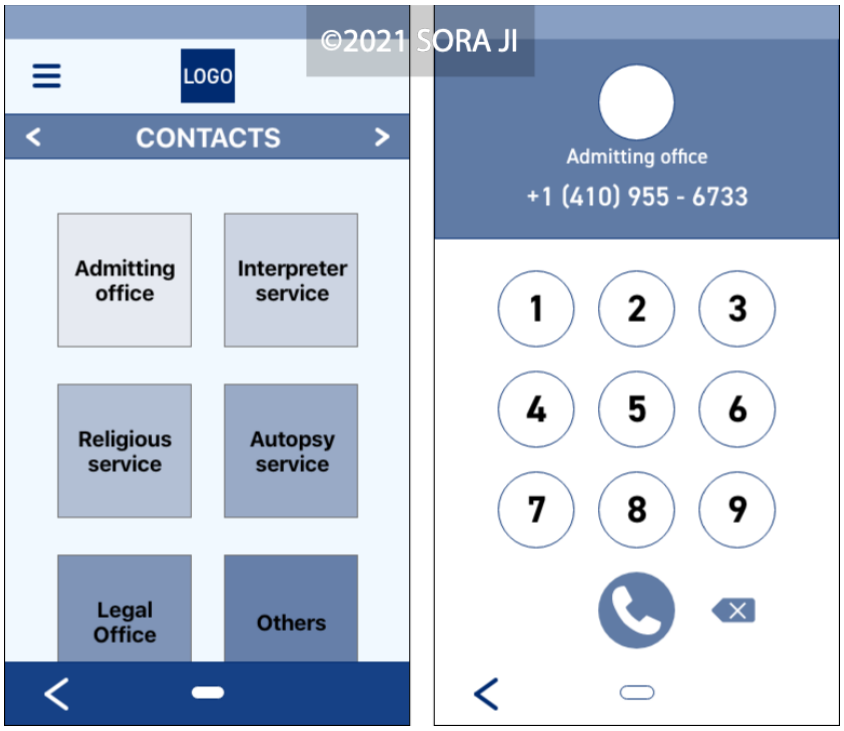


Figure 20. Layout for contacts. (Left: main page, Right: call page)

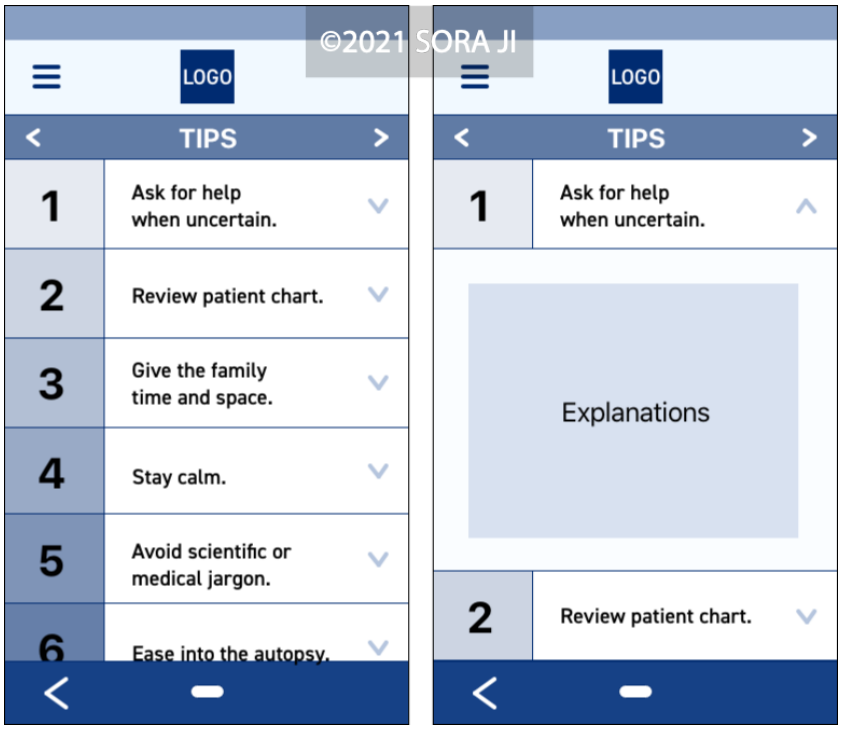


Figure 21. Layout for tips. (Left: main page, Right: individual content page)

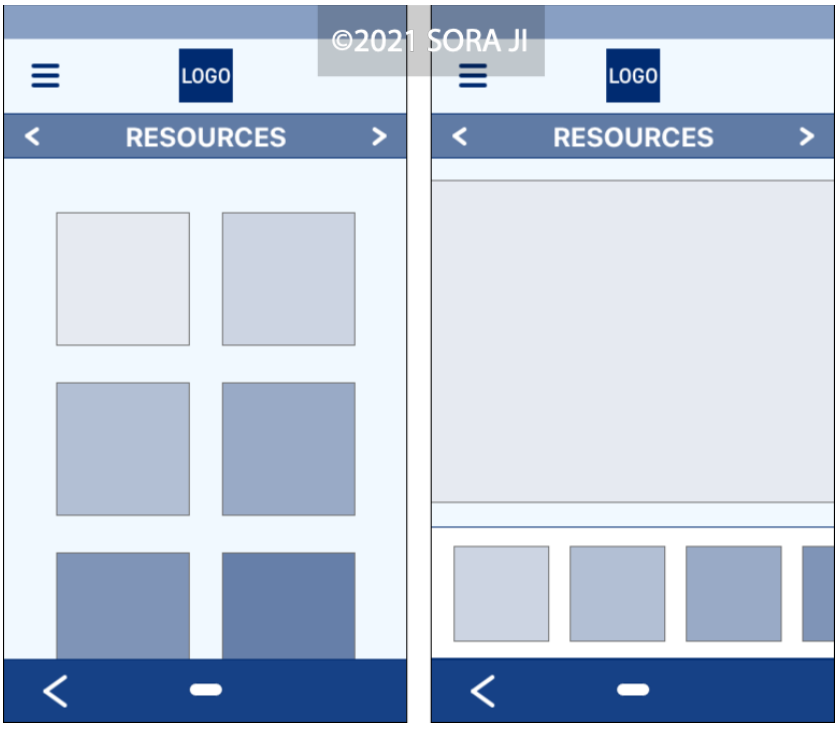


Figure 22. Layout for resources. (Left: main page, Right: individual content page)

c. Mobile app logo

The purpose of the mobile app is to support clinicians when requesting an autopsy consent. The mobile app was designed to improve the experience of both clinicians and families in this process. Therefore, the application logo was designed to show supportive imagery. This led to various ways to capture two individuals holding hands, showing support and help, and signifying agreement (Figures 23, 24).

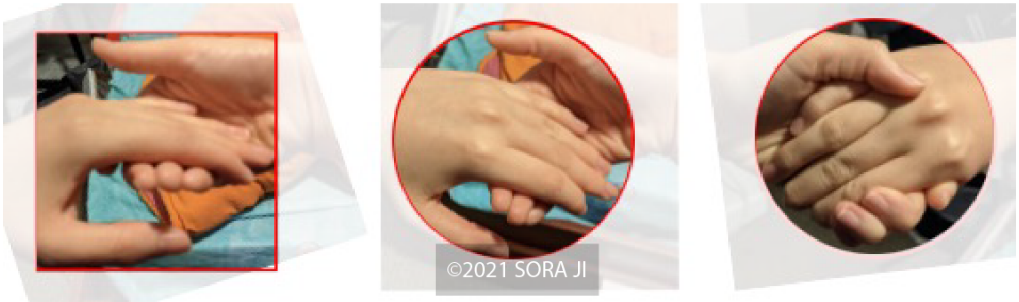


Figure 23. Ideation process for application logo.

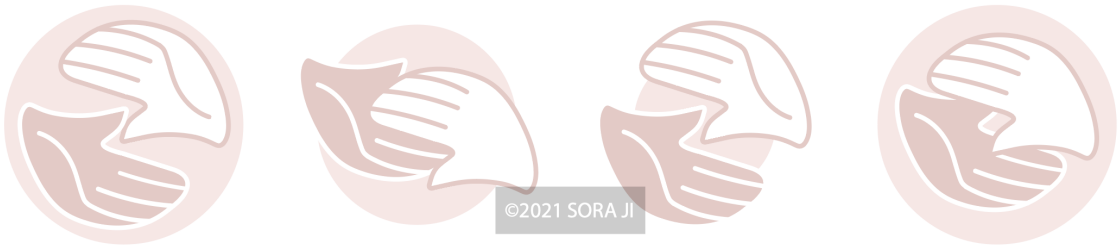


Figure 24. Logo idea.

4. Pocket guide

Information distillation and content selection

The pocket guide is the third component of the autopsy consent training material; it is a hand-held, laminated booklet with simple, clear illustrations, providing visual support for the families. The clinicians will keep it in their coat pocket and present it to the family when explaining details of an autopsy or the consent form. Considerations were made to ensure the visuals are not traumatizing to the family members of the deceased. The illustrations provide answers to frequently addressed concerns including determining the next-of-kin, effects of autopsy on open casket viewing, and timeline of the next steps the families would take. Visual information can help emotional or confused family members better understand and retain the information presented by the clinician.

Media selection

A hand-held booklet was selected as the format for the pocket guide. The pocket guide is intended to provide visual support to the family during the conversation. A printed, hand-held booklet can easily be stored in one of the pockets of the clinician's coat and can be shared with the family without being considered as impolite as utilizing a mobile device during this crucial conversation.

Prototype booklet

The prototype booklet created using Adobe Illustrator. Rough thumbnails were created, allowing multiple iterations for the final structure and color (Figures 25 - 28). One of each iteration was selected to be further developed as the final illustration. Consenting for an autopsy is tremendously stressful for families. Therefore, visual features of the illustration must be simple and easy to understand, so that the family can focus on the delivered information rather than on the visual assets.

a. Illustration 1: Order of legal next-of-kin in Maryland.

Autopsy consents can only be given by the legal next of kin. It is crucial that the clinician and family members are aware of the order of the next of kin, before the autopsy consent form is signed. Consent given by a wrong signatory is not legally valid, and may delay the autopsy consent procedure, leading to loss of valuable time-sensitive information. The information was organized through the use of a family tree, providing an intuitive view of the order of legal next of kin and their relationship with the decedent (Figures 25, 26).

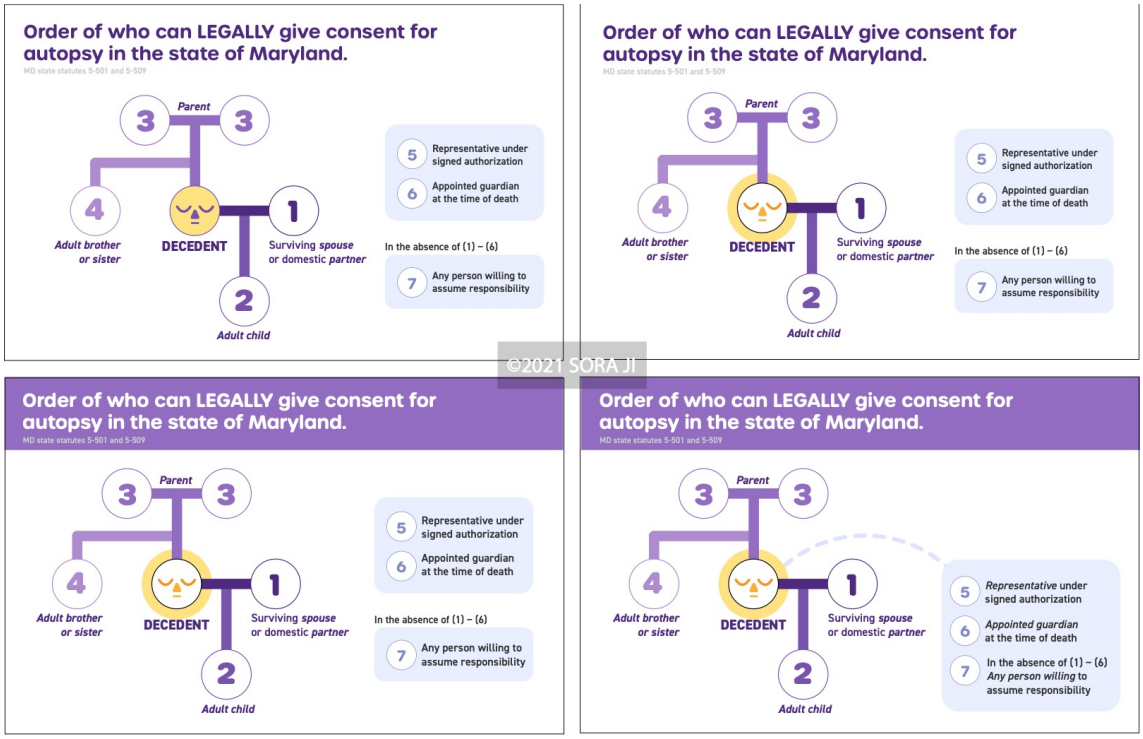


Figure 25. Screenshots of horizontal layout iterations for Illustration 1. *Text not meant to be read.*

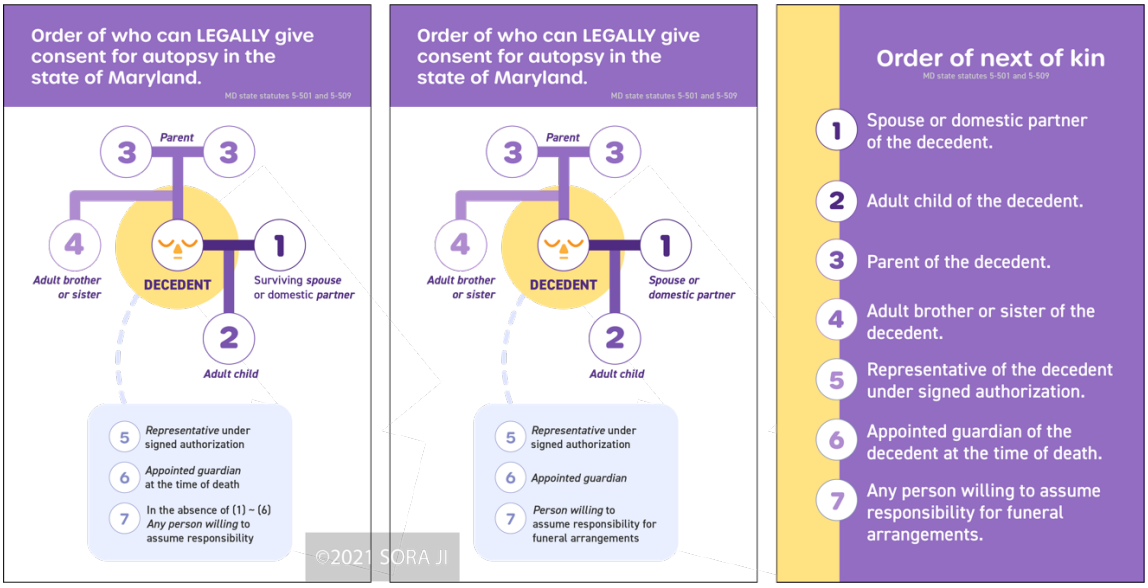


Figure 26. Screenshots of vertical layout iterations for Illustration 1. *Text not meant to be read.*

b. Illustration 2: Open casket viewing.

It is very common for families to worry about how an autopsy will affect an open casket viewing. This is important information for families, and can influence their decision whether or not to consent for an autopsy. Because the indication of where incisions are made in the body during autopsy can be upsetting to family members, it was determined that the most effective way to convey this concept was to depict areas of the body *not affected* by the autopsy: the face, hands, and legs/feet. Special consideration was given to how to depict that the *face* was not affected, while being truthful that the *whole head* did not fall into this statement i.e., the back of the head can be affected, but is an area that is not visible in an open casket viewing. A simple illustration of a deceased patient in an open casket without any incision marks or scars was included to provide further level of understanding and comfort for the family. Several iterations of the open casket viewing design concepts were explored (Figure 27).

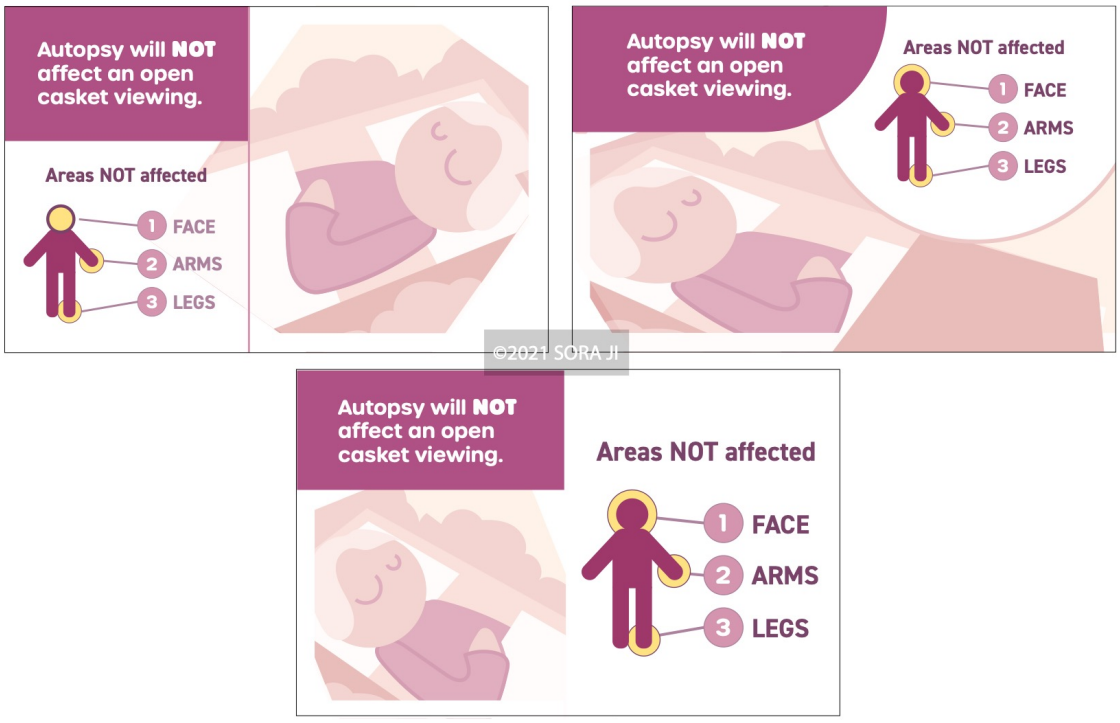


Figure 27. Screenshots of layout iterations for Illustration 2. *Text not meant to be read.*

c. Illustration 3: Next steps to prepare.

Family members overwhelmed with grief often have a hard time knowing “what to do next”. However, it is important that families are aware of the next step of events that will happen after they give consent to an autopsy. A simple, illustrated timeline with the next steps organized in chronological order will help the family know what to expect and make arrangements as needed. Icons were developed for each step and several iterations of the timeline design were explored (Figures 28, 29).

Figure 28. Screenshots of horizontal layout iterations for Illustration 3. *Text not meant to be read.*

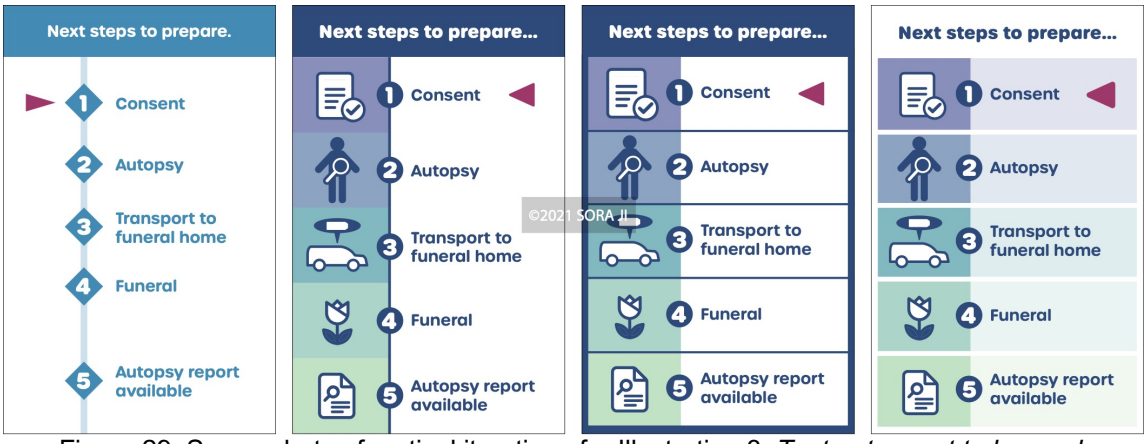


Figure 29. Screenshots of vertical iterations for Illustration 3. *Text not meant to be read.*

RESULTS AND DISCUSSION

Discussions with Johns Hopkins Hospital (JHH) clinicians identified the lack of educational and training material for requesting an autopsy consent. For most clinicians, learning opportunities only arose when the clinicians themselves had to request for autopsy consent. Organized, instructional material created by a medical artist can improve clinician training for obtaining autopsy consent. Prepared clinicians will be better informed and prepared to support the next-of-kin, resulting in clearer and more comfortable conversations. This will result in improved transparency, and more fully informed consents for autopsy.

Our goal was to design easily accessible educational references and training resources, to improve the experience of autopsy consenting for both clinicians and the patients' families. We designed a multi-OS, mobile compatible, electronic tool featuring visual resources for clinicians. The tool has three components: 1) a training module webpage, 2) a quick reference mobile app, and 3) a printed pocket guide.

1. Training module

Prototype Webpage

The prototype webpage provides a preview of the final functional website and its potential use. The prototype can be used as a guide and inspiration to create a future functional website (Figure 30). Design elements can be adjusted to match the Johns Hopkins Hospital (JHH) theme. The website was designed to be accessible to JHH clinicians and Johns Hopkins University School of Medicine students as an educational training resource; a version of it could also be useful for clinicians and educators at other hospitals and institutions.

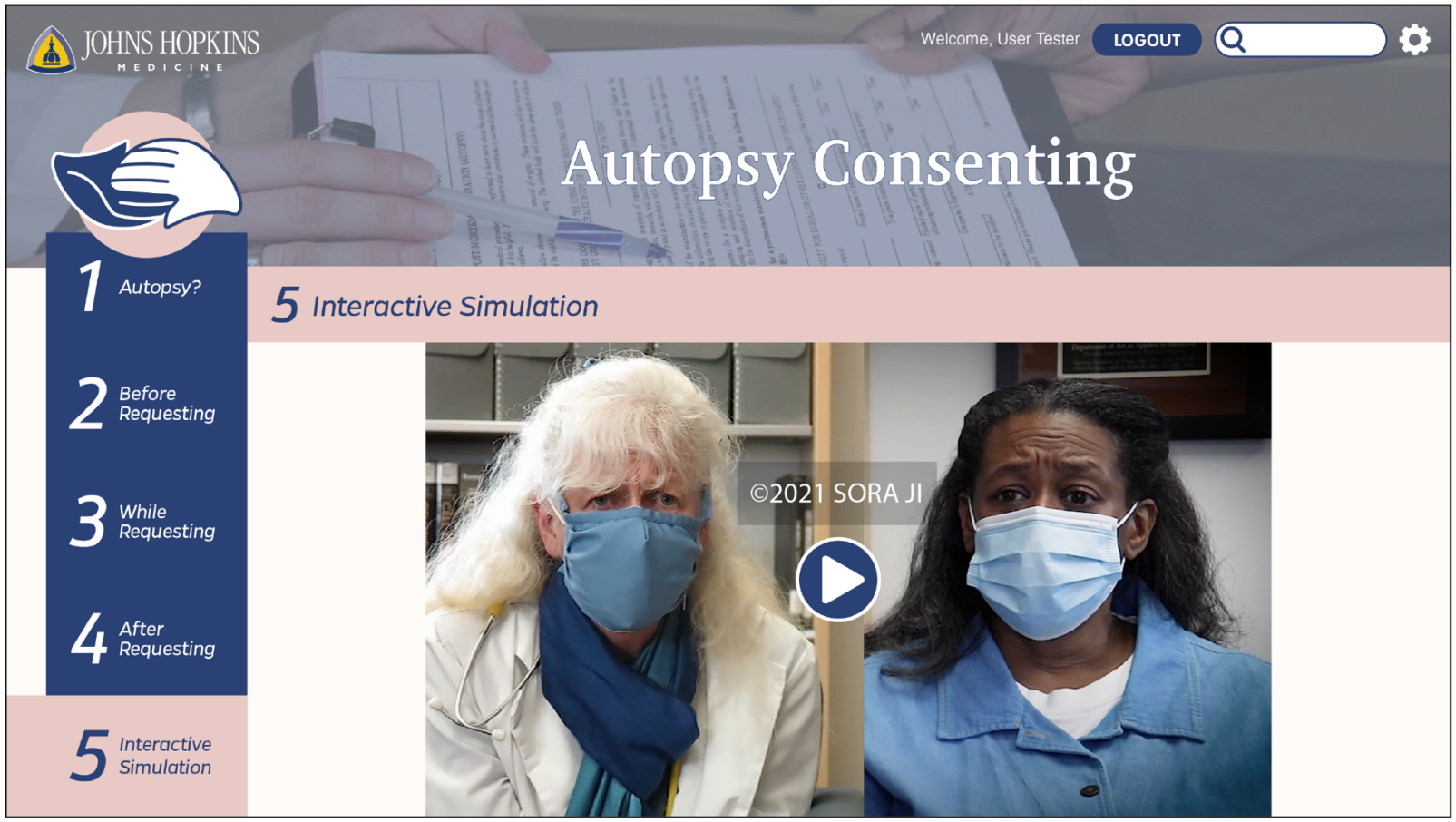


Figure 30. Prototype training module webpage.

Pre-simulation introduction

The pre-simulation section was designed as a brief introduction before the actual simulation (Figures 31, 32). Future development may include additional content, if needed. Supplemental scenarios can be filmed and edited so that the introduction starts with the clinician preparing to enter, rather than after entering, the room.

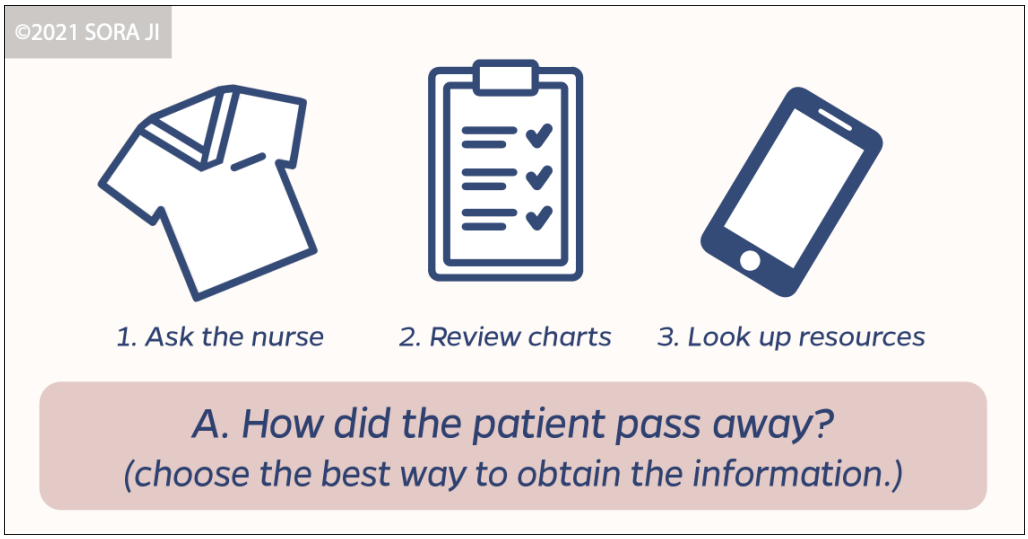


Figure 31. Prototype for pre-simulation introduction.

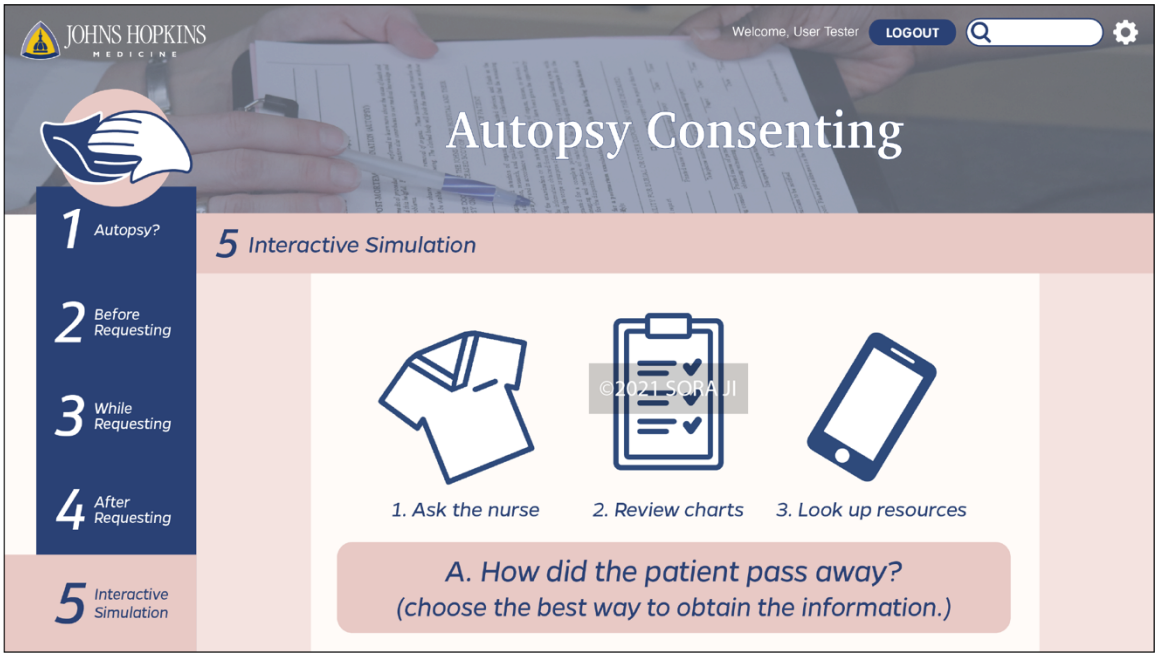


Figure 32. Prototype pre-simulation introduction placed within prototype webpage.
Not all text is meant to be read.

Interactive simulation

The interactive simulation addresses situations commonly experienced by clinicians when requesting an autopsy consent. The interactive 'choose your own adventure' format is organized to follow a central storyline starting from initiating the conversation and ending with hearing the family's final decision. Depending on the response the user selects for certain situations – responses that represent either great, neutral, or poor approaches – the patient's family's response also changes as the user continues the storyline in the interactive simulation.

a. Scenario

The scenario was designed to start when the clinician entered the room. However, future development may add scenes where the clinicians is tasked, on short notice, to obtain an autopsy consent from a patient they have never met, emphasizing the potential suddenness the clinician may face. This will emphasize the fact that clinicians often feel unprepared for the conversation.

b. Filming

We recorded using three different cameras from three different directions, which give us three different views (Figures 33 - 35). Through editing, we interweaved the three separate recordings and created one video, which made it possible to highlight the easily missed, subtle non-verbal cues including facial expression and body language (Figures 36 - 39). This editing enables the viewer to focus on such subtle cues, creating a more engaging and meaningful learning experience for the viewer.

Figure 33. Wide recording angle capturing both the clinician and family member (SP).

Figure 34. Over the shoulder angle focusing on the clinician.

Figure 35. Over the shoulder angle focusing on the family member (SP).

Figure 36. Closing up distance through editing. (Left: before editing, Right: after editing)

Figure 37. Zooming in to emphasize family member's facial expression.

Figure 38. Combining side to side view through editing.

Figure 39. Emphasizing the family member’s expression through editing.

c. Interactive simulation

The edited clips were imported into Camtasia and 'Interactive Hotspots' were used to create an interactive simulation (Figures 40, 41). The interactive simulation was designed to be embedded into the training module webpage (Figure 42). It could also be used independently for educational purposes. Clinicians and students can finish the simulation activity in advance then discuss their experiences during in-person training or courses, in a flipped classroom model.

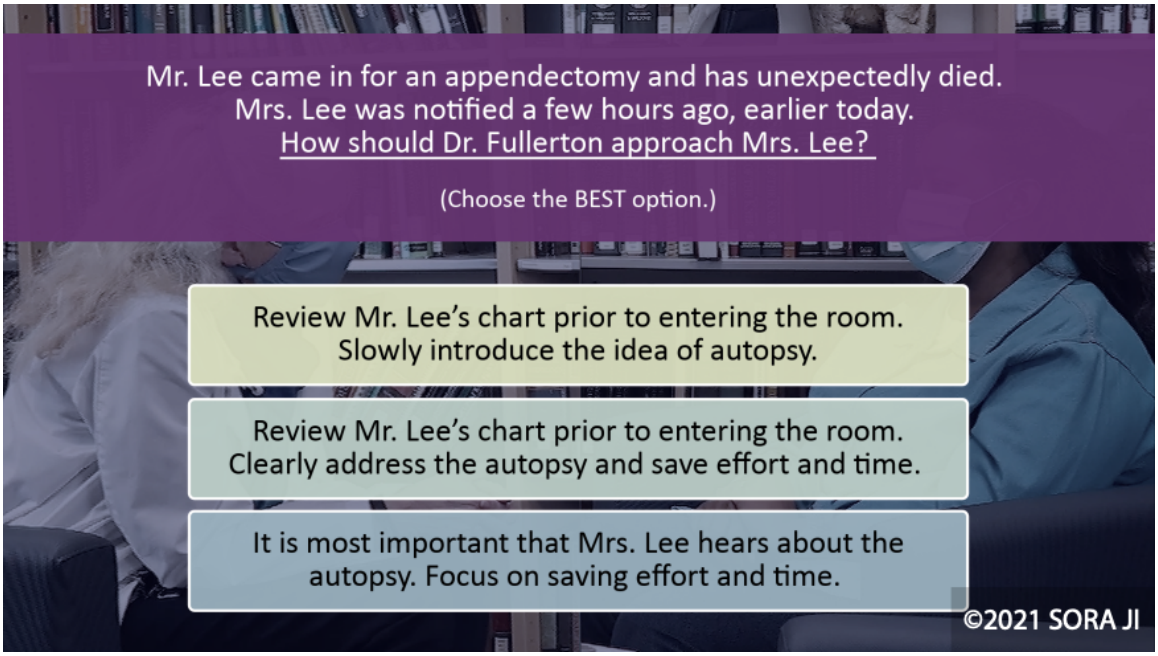


Figure 40. Prototype of interactive simulation.

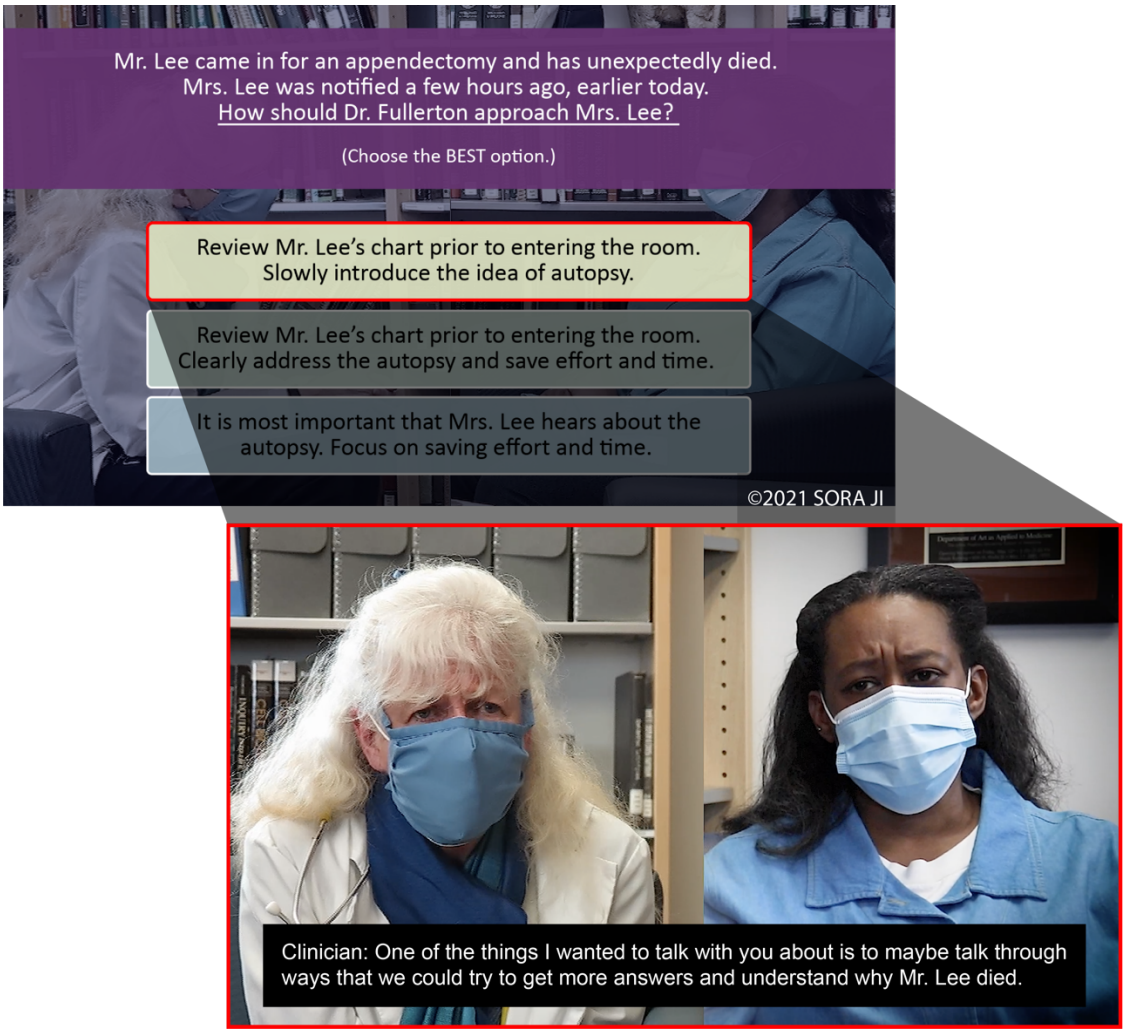


Figure 41. Example of story progression within interactive simulation.

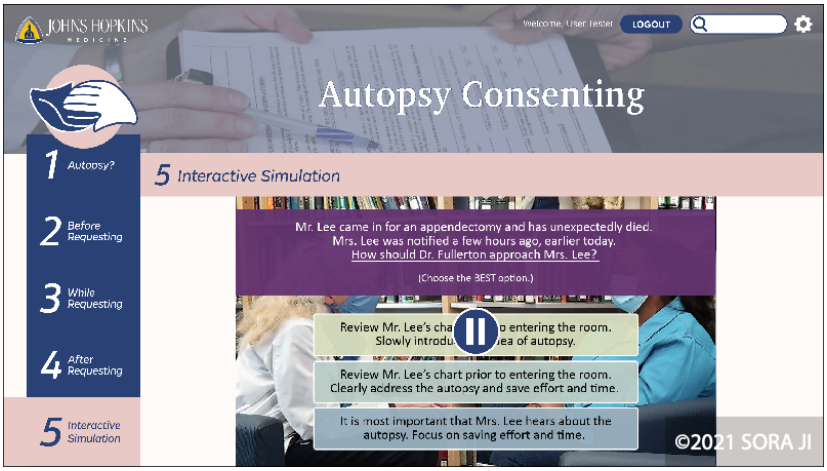


Figure 42. Interactive simulation placed within prototype training module webpage. *Text not meant to be read.*

2. Quick Reference mobile app

The prototype for the mobile app was created with Adobe XD (Figure 43). With future developments, the prototype can be a useful reference when creating the final functional application. We envision the app to be accessible to all JHH clinicians. Additional content can be added based on user testing and user needs. It will be important to ensure the app is functional on both android and Apple devices and is compatible with tablets

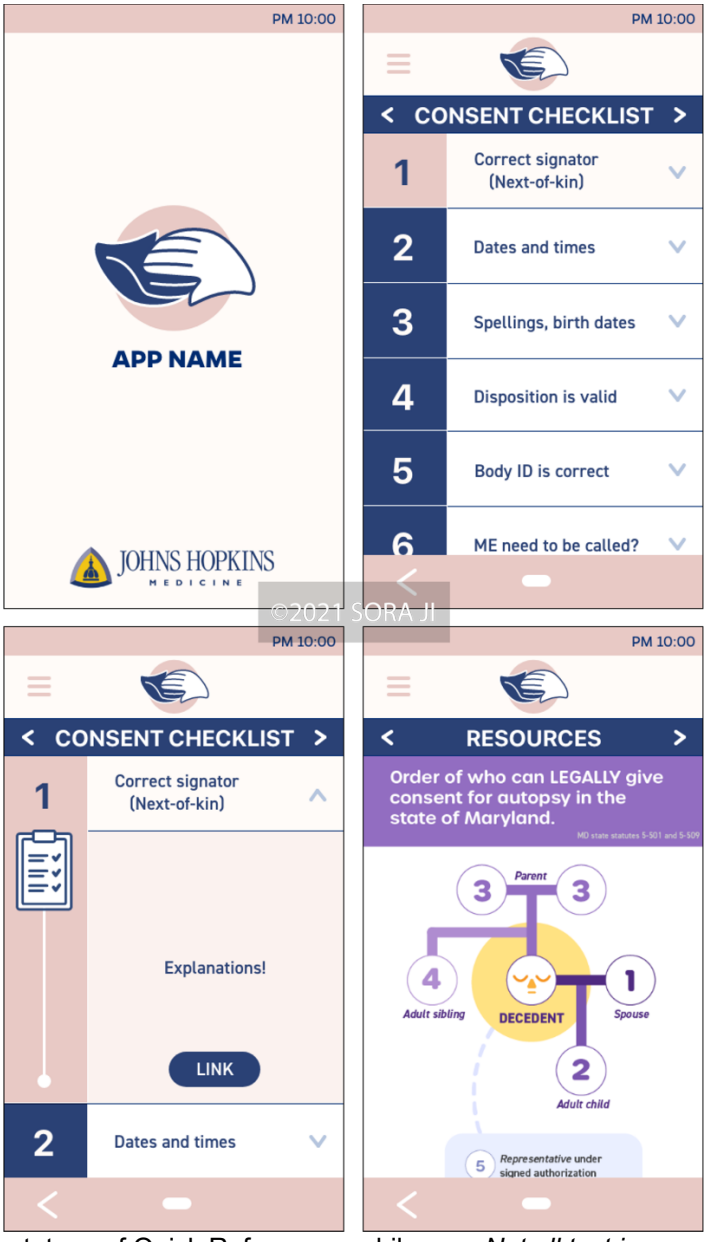


Figure 43. Prototype of Quick Reference mobile app. *Not all text is meant to be read.*

3. Pocket guide

The pocket guide includes three illustrations: 1) order of legal next-of-kin in Maryland, 2) open casket viewing, and 3) next step to prepare. The objective was to create clean and non-traumatic illustrations. We envision the printed, laminated pocket guide to be accessible to all JHH clinicians. With future developments, additional contents can be added based on user testing and user needs.

a. Illustration 1: Order of legal next-of-kin in Maryland.

Attention was given to information hierarchy. A bright yellow circle was placed behind the decedent to catch the eye of the viewer. This bright yellow circle contrasts the nearby purple and blue shades, further emphasizing the decedent. Through the use of different shades of purple, we have created hierarchy within the family tree structure. Darker shades of purple attract the viewers eyes, which will naturally follow down the gradient from darker purple to lighter purple as the viewer simultaneously follow down the order of the legal next-of-kin (Figure 44).

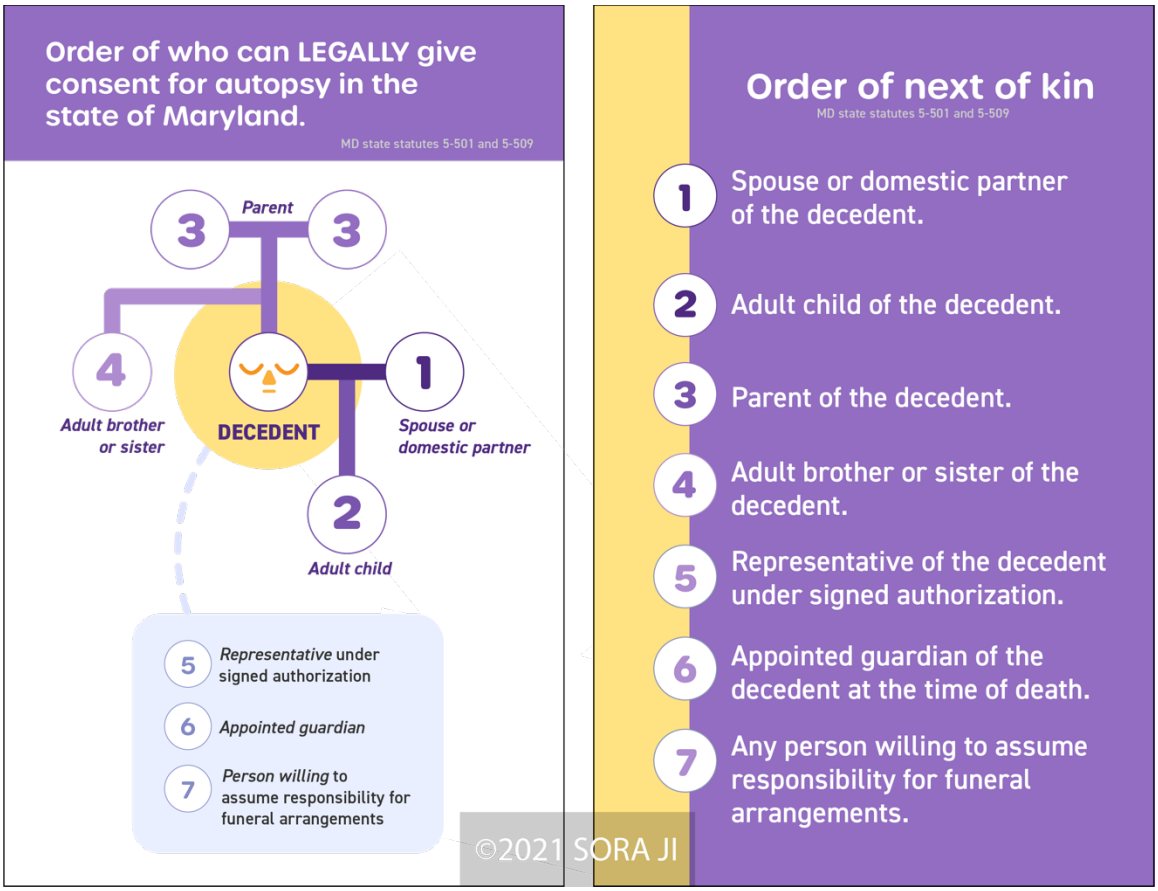


Figure 44. Illustration 1: Order of legal next-or-kin in Maryland. (Left: front, Right: back)

b. Illustration 2: Open casket viewing.

Families can feel very emotional while discussing funerals and open casket viewings. Therefore, attention was given into creating a gentle, calm, and peaceful atmosphere. Various shades of soft peach and pink was used to depict the funeral. A human icon was used to depict the areas not affected by the autopsy. Magenta was used to make the important information pop-out and yellow was used to highlight specific areas. We kept the images fairly cartoonish to prevent causing any anxiety or additional negative emotions to the family members. It was also our intention that the illustrations not suggest any specific religion or nationality (Figure 45).

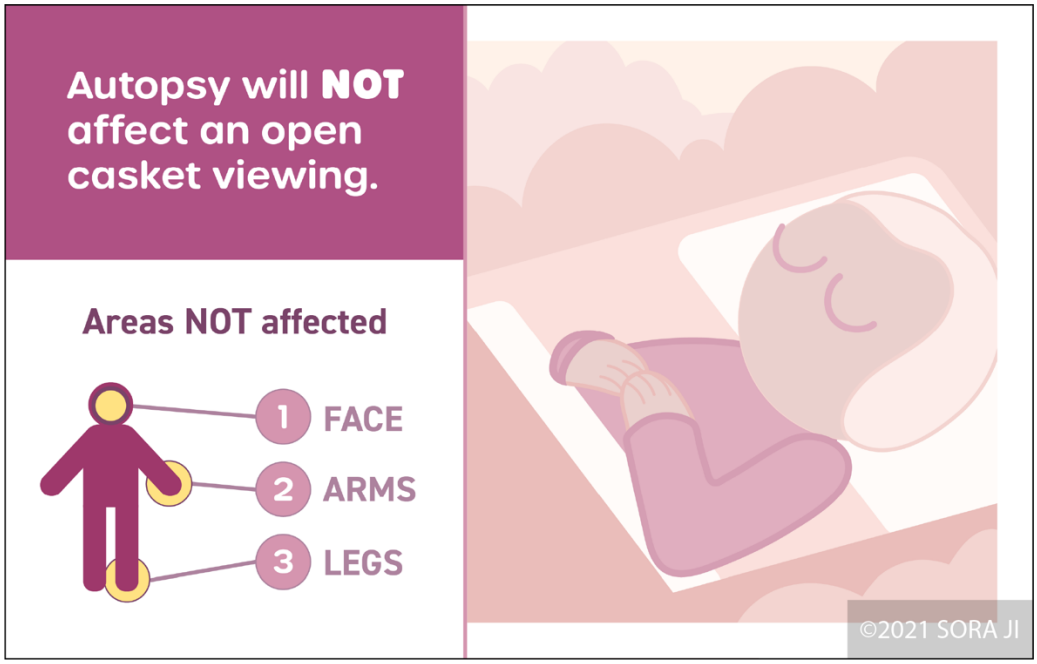


Figure 45. Illustration 2: Autopsy will NOT affect an open casket viewing.

c. Illustration 3: Next steps to prepare.

To help families prepare and make arrangements after they give their consent for an autopsy, attention was given to creating a simple, easy to follow linear flow. A gradational color palette starting from a duller cool periwinkle to a brighter warm light green was used to suggest progression and add visual interest. Simple icons symbolizing each step will also add visual interest and help the family take in the information. Once again, the images are kept fairly simple and cartoonish to prevent causing any negative emotions to the family members. It was also our intention that the illustration not suggest any specific religion or nationality (Figure 46).

Figure 46. Illustration 3: Next steps to prepare.

4. Conclusion and future directions

Discussing autopsies can be extremely stressful, not only for the grieving family members, but also for clinicians tasked to request the autopsy consent. Through our project we have ideated and designed a comprehensive learning experience providing organized educational material, virtual interactive training opportunities, and supportive visual resources. Our design will help improve communication and experiences for both clinicians and families during the autopsy consenting process - the hardest teachable moment. Our project has laid down the groundwork for further development of the tools, which will be very beneficial once fully implemented.

This project has been a valuable learning experience during which we explored and designed a systematic learning experience covering three different levels of information. Depending on the amount and depth of information covered, each level was assigned a different media and platform to effectively communicate the information. When all three levels are combined, the flow of knowledge created by the amount of information and method of communication creates an organic learning experience for the audience. This project has provided an opportunity to explore the proper selection of media, which is one of the important factors that decides the effectiveness of medical visualization and communication. Future directions will include finalizing the three different platforms, while adding or updating the contents if needed.

Through the novel use of Standardized Patients and interactive-media-building software alongside 2D illustrations, we have started to explore the effectiveness in information delivery when allowing opportunities for engagement and interaction in medical visualization. This opportunity has shed light on the potential use of such hybrid media in creating highly effective medical visualization projects at the Johns Hopkins School of Medicine, in the Department of Art as Applied to Medicine. For example, inserting clips of live action Standardized Patient recordings into 2D animations and/or interactives can enhance the realism and learner engagement.

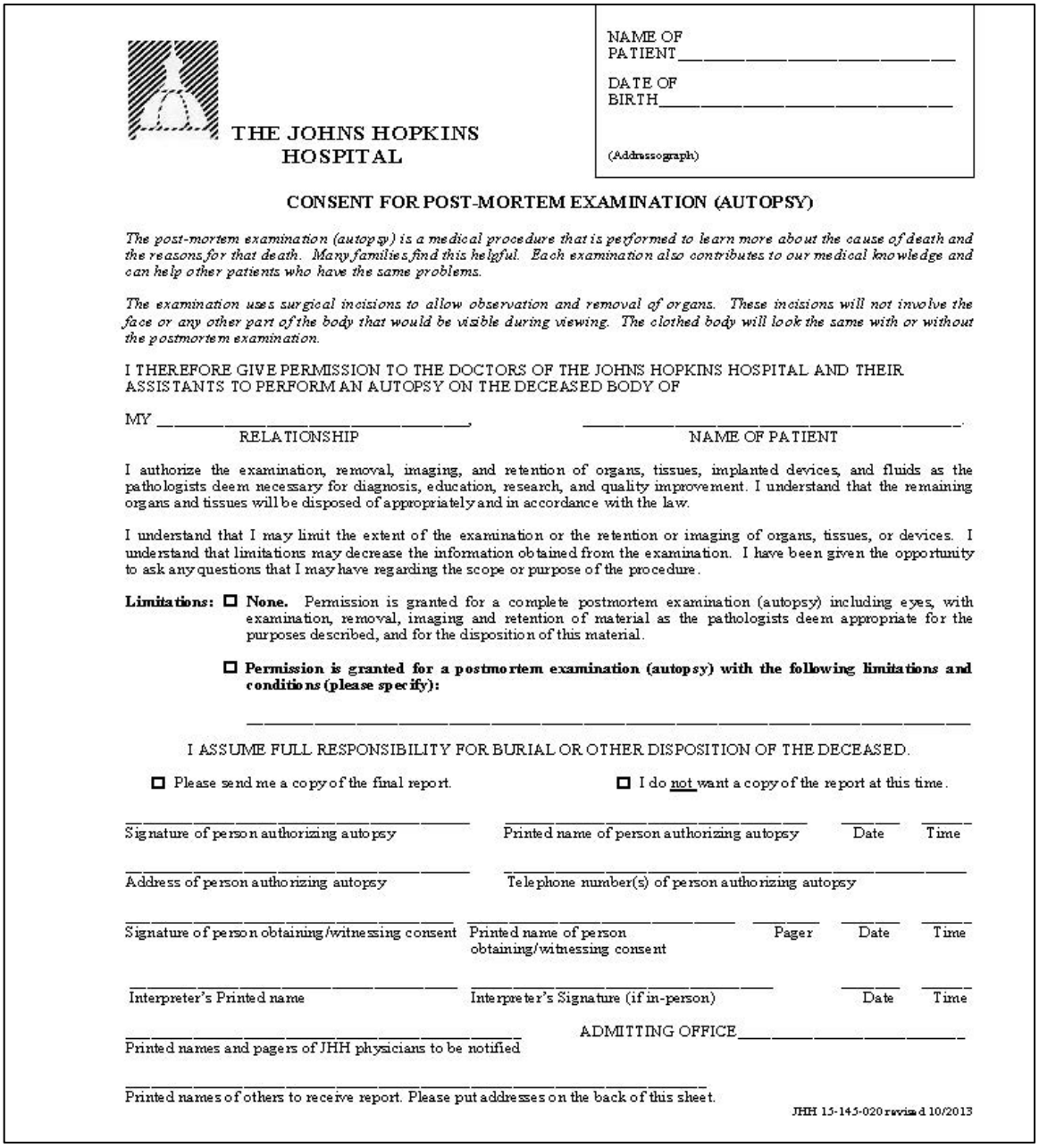
It has also come to our attention that, considering the number of autopsies conducted at the Johns Hopkins Hospital (JHH), clinicians and patients' families would benefit from having an appointed person or office in charge of all autopsy related business. Efficient communication between patient's families, clinicians, and the hospital will not only improve the consenting process, but also the process for returning autopsy results to the patient's families. Future systematic changes, in conjunction with the tools designed for this project, will improve the experience for all during this most difficult teachable moment: autopsy consenting.

5. Access to Assets resulting from this thesis

Access to the images, recordings, and prototypes resulting from this thesis can be viewed by contacting the author at soracji@gmail.com. The author may also be reached through the Department of Art as Applied to Medicine via the website www.hopkinsmedicine.org/medart

APPENDICES

Appendix A: The Johns Hopkins Hospital Autopsy consent form.



THE JOHNS HOPKINS HOSPITAL

NAME OF PATIENT_____

DATE OF BIRTH_____

(Addressograph)

CONSENT FOR POST-MORTEM EXAMINATION (AUTOPSY)

The post-mortem examination (autopsy) is a medical procedure that is performed to learn more about the cause of death and the reasons for that death. Many families find this helpful. Each examination also contributes to our medical knowledge and can help other patients who have the same problems.

The examination uses surgical incisions to allow observation and removal of organs. These incisions will not involve the face or any other part of the body that would be visible during viewing. The clothed body will look the same with or without the postmortem examination.

I THEREFORE GIVE PERMISSION TO THE DOCTORS OF THE JOHNS HOPKINS HOSPITAL AND THEIR ASSISTANTS TO PERFORM AN AUTOPSY ON THE DECEASED BODY OF

MY _____, _____.
RELATIONSHIP NAME OF PATIENT

I authorize the examination, removal, imaging, and retention of organs, tissues, implanted devices, and fluids as the pathologists deem necessary for diagnosis, education, research, and quality improvement. I understand that the remaining organs and tissues will be disposed of appropriately and in accordance with the law.

I understand that I may limit the extent of the examination or the retention or imaging of organs, tissues, or devices. I understand that limitations may decrease the information obtained from the examination. I have been given the opportunity to ask any questions that I may have regarding the scope or purpose of the procedure.

Limitations: ☐ **None.** Permission is granted for a complete postmortem examination (autopsy) including eyes, with examination, removal, imaging and retention of material as the pathologists deem appropriate for the purposes described, and for the disposition of this material.

☐ **Permission is granted for a postmortem examination (autopsy) with the following limitations and conditions (please specify):**

_____

I ASSUME FULL RESPONSIBILITY FOR BURIAL OR OTHER DISPOSITION OF THE DECEASED.

☐ Please send me a copy of the final report. ☐ I do not want a copy of the report at this time.

_____ _____ _____ _____
Signature of person authorizing autopsy | Printed name of person authorizing autopsy | Date | Time

_____ _____
Address of person authorizing autopsy | Telephone number(s) of person authorizing autopsy

_____ _____ _____ _____ _____
Signature of person obtaining/witnessing consent | Printed name of person obtaining/witnessing consent | Pager | Date | Time

_____ _____ _____ _____
Interpreter's Printed name | Interpreter's Signature (if in-person) | Date | Time

_____ ADMITTING OFFICE_____
Printed names and pagers of JHH physicians to be notified

_____
Printed names of others to receive report. Please put addresses on the back of this sheet.

JHH 15-145-020 revised 10/2013

Appendix B: Questions and compiled answers for discussions with clinicians at the Johns Hopkins Hospital.

a. Questions for autopsy consenters

Thank you for agreeing to discuss autopsy consenting with me. Drs. Hooper, Sandone, and I will be developing a new tool to assist clinicians in autopsy consenting. These are the questions I would like to cover in our time together.

1. Have you received training on asking for autopsy consent? How was this training similar/different from your actual experience?

2. Please describe an experience of a successful (everything went smoothly) and unsuccessful (unexpected complications) autopsy consenting process.

3. When asking for consent, can you generalize the reactions in the situations of:

parent consenting for autopsy of young child
parent consenting for autopsy of adult child
adult child consenting for autopsy of parent
cause of death (sudden vs anticipated)

4. What are most frequent questions you receive from the patient families regarding the autopsy process? Most difficult to answer? Most unexpected?

5. How do you phrase your request to be most emotionally accommodating to the family?

6. What should a person asking consent *never* say to the family?

7. If you had only a few minutes to give final advice to a novice clinician who will be asking for consent, what tips will you give?

8. Can you think of anything else that it would important to consider as we develop an electronic tool for clinician education and practice with autopsy consenting?

b. Compiled answers for discussions with clinicians

1. Have you received **training** on asking for autopsy consent? **All responded NO**
How was this training similar/different from your **actual experience**?

Learning moments
- Apprenticeship, internship, residency, pathology residency.
- Teaching courses, accumulated experience, received training for pronouncing death.

Struggles
- No exposure to training or courses → suddenly told to ask for consent.
- So much to learn and focus on → less emphasis on death and autopsy.
- No opportunity to observe the asking process and think about it.

Efforts made
- Try to bring over residents when asking.
- Courses for med students → walk through scenarios.
- Workshops → discuss emotions and scenarios.

➡ **Prior exposure** to the asking **process** and discussion on **empathy** can be helpful.

2. Please describe your experience of a **successful** (everything went smoothly) and unsuccessful (unexpected complications) autopsy consenting process.

Success factors

1. Right timing + compassion ◆◆◆
   - Give the family space and time to process. No rushing. Show respect and empathy.
2. Special / abnormal cases ◆◆
   - Younger patients, criminal investigation cases, unexpected deaths.
3. Normalization
   - Keep a script and make a smooth routine for yourself. Know how to contact patho.
4. Honesty
   - Give honest opinions and answers to questions
5. Strong belief in the need of an autopsy ◆◆
   - When you believe an autopsy will be beneficial, let the family know.
6. Good relationship with the patient and family ◆◆
   - Easier to approach families regarding autopsy.

Others: Lawyer's request, patients wanting to retaliate, etc.

2. Please describe your experience of a successful (everything went smoothly) and **unsuccessful** (unexpected complications) autopsy consenting process.

Failing factors

1. Bad timing + Rush ◆◆
   - Middle of the night, rushing families into a decision.
2. Severed communication
   - Infant taken to NICU > communication lost > no opportunity to ask consent.
3. Family's emotions ◆◆
   - Novice clinicians often back away when families express deep sadness.
4. Religious requests
   - Unsure how to help families with religious requests (esp. with fast autopsy).
5. Tangled paperwork
   - Patient donated body > cannot locate documents > frustrated families.
6. Negative image of autopsy ◆◆
   - Families think autopsy is disrespectful or defiling.
7. Unfamiliar with patient's family (most common situation)
   - Harder to approach grieving families regarding autopsy.

3. When asking for consent, can you generalize the **reactions** in the situations of:

Parent consenting for young child

- **Shock, anger, denial**
- May initially refuse autopsy, but later realize it can give answers.

* In cases of genetic termination, death is expected. However, the option for autopsy may still be a surprise.

Parent consenting for adult child

- **Chronic illness: Relatively less shock**
- **Unexpected: shock, anger, denial**
- More likely to want an autopsy

* Parents will wonder what they could have done differently or be more suspicious about the hospital care.

Adult child consenting for parent

- **Relatively less shock.**
- Parents likely discussed death with child.
- Less likely to want an autopsy.

* Parents will often donate their bodies and the children will try to honor their will. Clinicians often unsure what to do.

Expected vs Unexpected

- **Expected: Relatively less shock**
- Less likely to want an autopsy
- **Unexpected: shock, anger, denial**
- More likely to want an autopsy

4. What are most **frequent questions** you receive from families? Most difficult to answer? Most unexpected?

1. **Funeral related**
   - Can we have an open casket?
   - When can we have the funeral / will it delay the funeral?
   - How do we connect with the funeral home?

2. **Autopsy related**
   - How is the incision going to be made? (*patient had extremely fragile skin)
   - Can you return all the organs?
   - What is going to happen during autopsy?
   - Will I have to pay for it / who pays how much?

3. **Culture / Religion related** (https://emedicine.medscape.com/article/1705993-overview)
   - Muslim/Jewish: can the body be buried within 24hrs? (*may need to involve imam/rabbi)

4. **Processing death of loved one**
   - How long can I stay with the body before it is taken away?

5. **Receiving Results**
   - When will I get the results?
   - Who can I contact to ask about the results?

5. How do you **phrase** your request to be most emotionally accommodating to the family?

1. **Show compassion**
   - I am so sorry for your loss. I may need to ask you some questions is it okay if I do it now?
   - Nothing I say will make this better, but I am hoping to get information needed to best care for you and your loved one.

2. **Address their worries and offer help**
   - Do you have any questions?
     → What questions are running through your mind? I can help answer those questions.
     * If death is addressed early: in the event that the patient passes away, is there anything we should be aware of to honor your religion or culture?

3. **Use friendly and warm words**
   - (Infant cases) Autopsy / post-mortem exam → we will exam the baby
   - Do you want an autopsy? → Would you consider and want to pursue the procedure (autopsy)?
   - Did your loved one want an autopsy? → Did your loved one ever share interest in ~

4. **Normalize / standardize the language**
   - By regulation we also offer all families an autopsy, should they wish one.

5. How do you **interact** with the family in an emotionally accommodating way?

1. **Introduce yourself and show empathy**
   - Build familiarity with the patient's family and acknowledge their loss.

2. **Make sure the family is okay**
   - Ask if they need water, more chairs, religious support, or anything.

3. **Ease into the topic**
   - We always offer the option of having an autopsy. Do you know what that is? Have you heard about it?

4. **Give the family time + be available**
   - Give the family time to process their loved one's death and think. Let them know you will come back later, give them your contact, and step away.

5. **Appreciate their help and apologize for any inconveniences.**
   - Let the family know their decision will not only give them closure but also help others; thank them.
   - In case of fast autopsy, apologize for moving the body early.

6. What should a person asking consent ***never*** say to the family?

1. **Words with negative connotations**
   - Dissection, Removal of organs, Surgical incisions (may evoke surgery trauma)
   - Any words that sound traumatic, destructive, or preserving.

2. **Unnecessary details**
   - Don't force information that the family does not need to know or is irrelevant.
   - Be truthful, but don't explain every single detail of the procedure unless asked.
     (*novice clinicians often use this as a crutch)

3. **Phrases showing uncertainty**
   - Families want to know that YOU know what you need to know.
   - Families may think you are covering up something.

4. **Aggressive suggestions**
   - You may suggest an autopsy, but the family always has the final say.
   - Never use phrases that may seem like you are exerting power.

Do not hesitate to use the word 'body'.

7. If you had only a few minutes to give final advice to a novice clinician who will be asking for consent, what **tips** will you give?

1. Do not be scared to ask for the nurse's help or company.
2. Read the room and get the right timing.
3. Review the chart and talk to the bedside nurse to learn about the family and their dynamics before interacting with the family.
4. Give the family time and space; come back later if needed.
5. If it's your first time, notify the family and let them know it may take longer than usual, but you are trying your best.
6. Remember this is someone's saddest day and stay in touch with humanity and compassion.
7. Create a stepwise routine for a smooth process.

7. If you had only a few minutes to give final advice to a novice clinician who will be asking for consent, what **tips** will you give?

8. Stay calm; there is nothing you should and can *fix*.
9. Realize the family is most likely not angry or upset because of you.
10. Try not to use scientific or medical jargon.
11. Try to use less emotionally charged words but don't beat around the bush.
12. You might say wrong things, but if it's coming from a good heart, families will know.
13. If the talk did not go well, ask if you can come back later and start the conversation again.
14. Explaining the service provided and then mentioning the procedure might help families realize their need for autopsy, while circumventing the initial negative impression.

8. Is there anything else **important to consider** as we develop an electronic tool for clinician education and practice for autopsy consenting?

Content

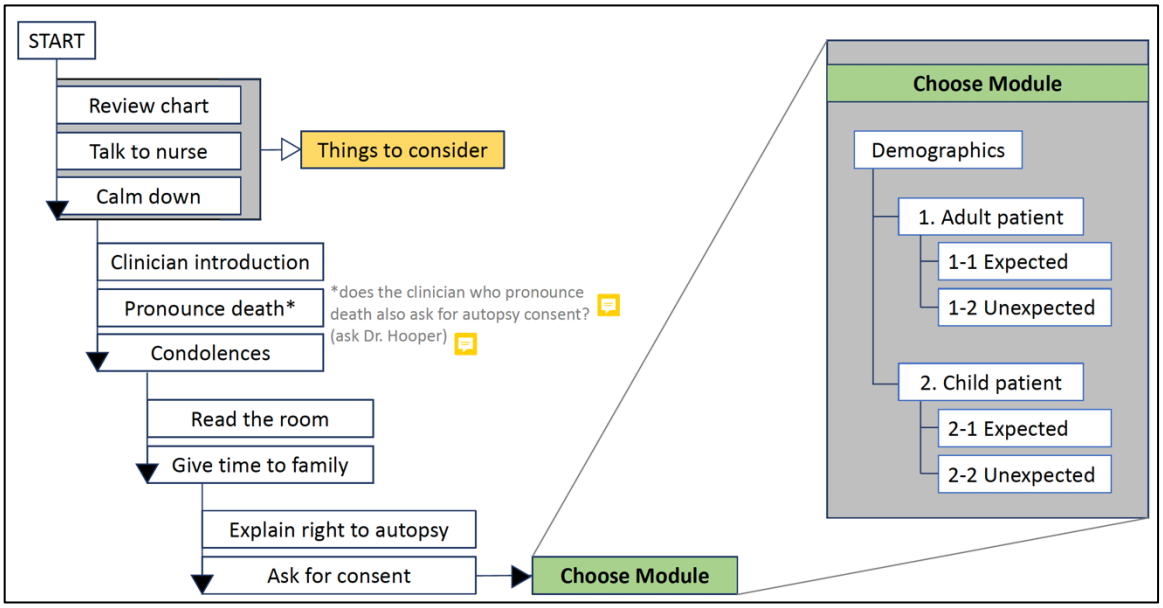
1. Explanations for how to approach the family.
2. Discuss common questions and their answers.
3. Clinicians often don't know the details (process, funeral, contact person, etc.)
4. How can the clinicians access the results.
5. Who can clinicians contact for details regarding autopsy?
6. Video of the process emphasizing the emotions, body language, non-verbal cues.

Format

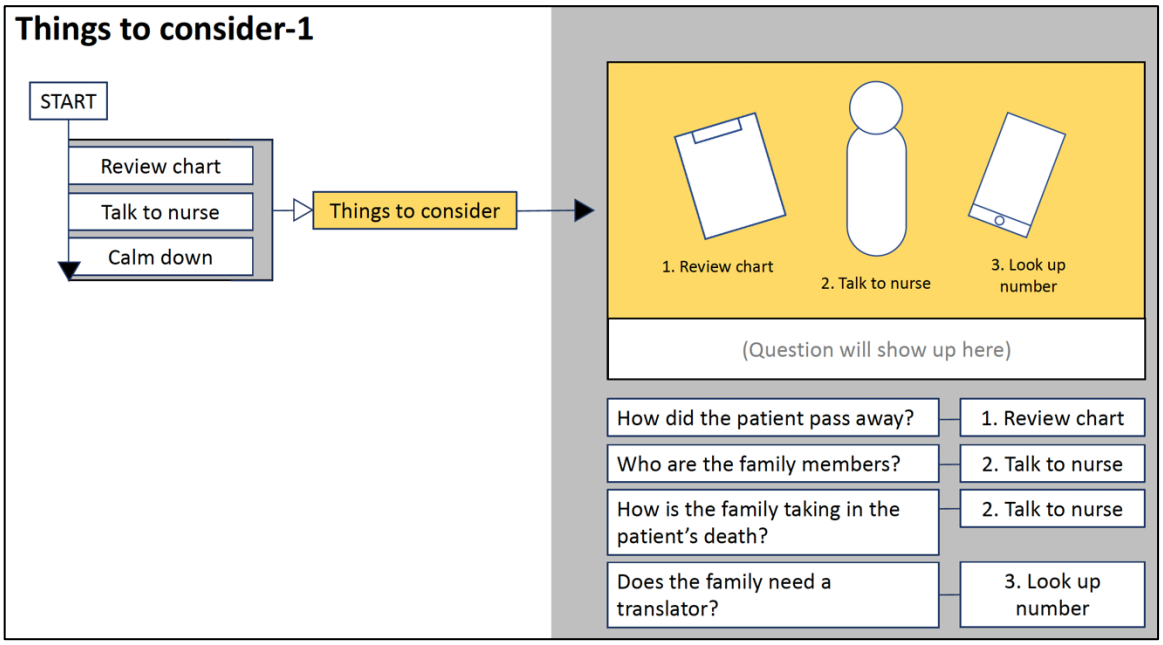
1. Must be mobile compatible (smartphone + tablet) and east to access when needed.
2. Aim for clinicians who are in their 20's
3. Make it brief and to the point.
4. If you are going for a broader audience outside of Hopkins, you might want to be less detailed.
5. Could it have a checklist or a pocket guide?

Appendix C: Designing flow for the training module.

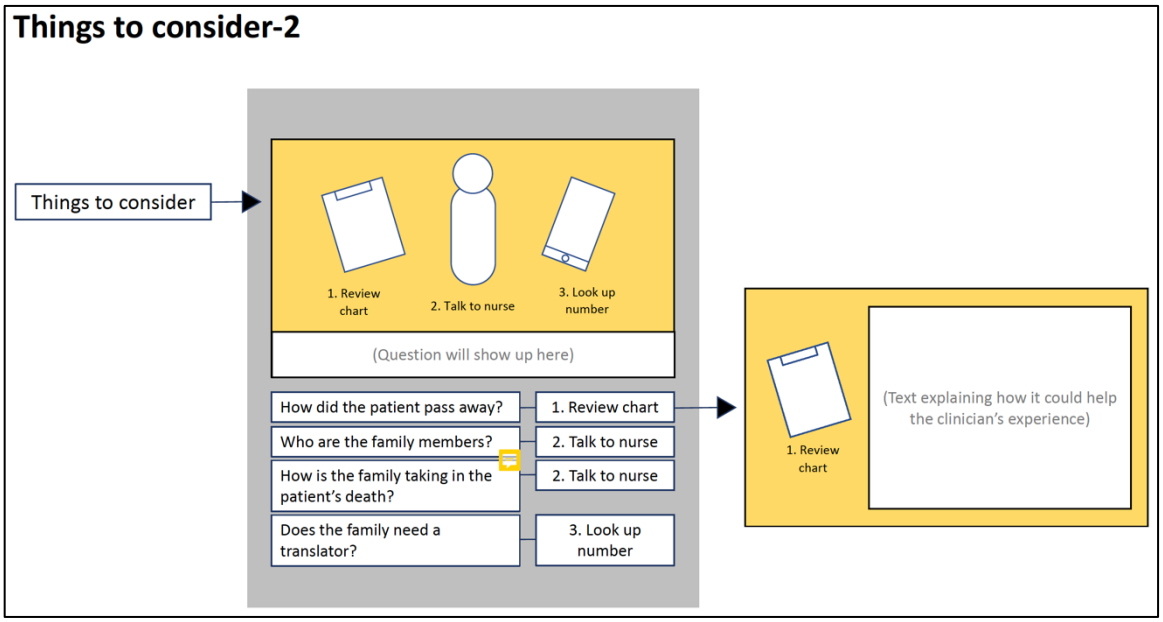
1. Comprehensive view of flow.



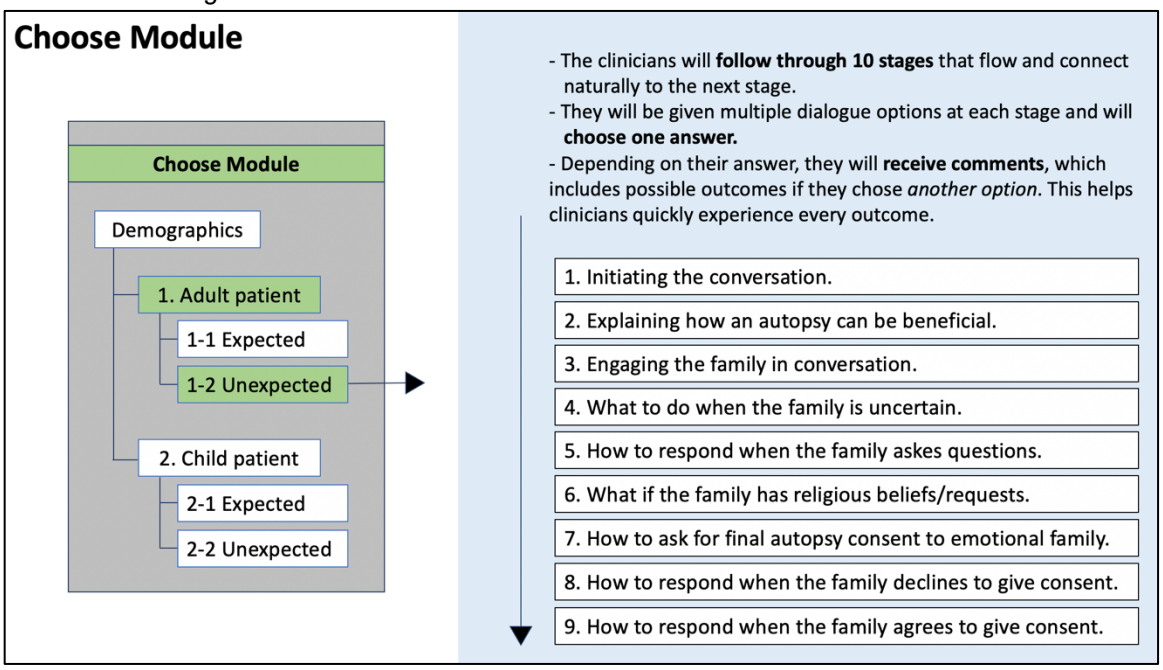
2. Pre-simulation introduction design - 1



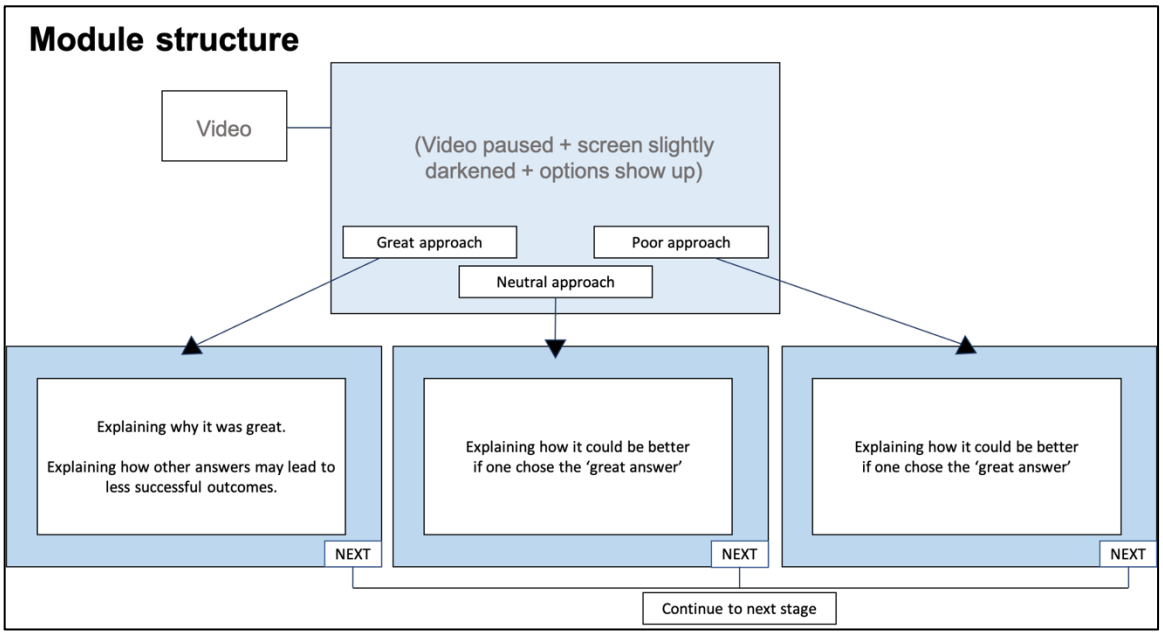
3. Pre-simulation introduction design – 2 (Not all text meant to be read).



4. Choose training module



5. Module structure



Appendix D: Script for 'interactive simulation' live action filming.

< Structure of the conversation >

1. Initiating the conversation
Objective: Initiate the conversation for an autopsy while providing the spouse/family emotional support. Introduce self and use the name of the family member to whom you are speaking.

2. Explaining how an autopsy can be beneficial.
Objective: Explain the benefits of an autopsy. Help the family understand an autopsy may have many other benefits including exploring the cause of death.

3. Listening and understand where the family stands.
Objective: Read the room and gauge the family's comfort level. Do not assume the family has prior knowledge about what is involved with an autopsy.

4. How to respond when the family asks questions about the autopsy procedure.
Objective: Give the family necessary information. Try not to put the burden of asking questions on them or giving unwanted discomforting details without checking if it's okay with them. Do not use medical jargon.

5. What if the family has requests due to religious beliefs or other reasons.
Objective: Know that families can submit special requests for the autopsy. If unsure, be aware of the resources that can be used to get answers.

6. How to ask for final autopsy consent to an emotional family.
Objective: Give time and space to the family. If they are not ready to give the final consent at the moment, or need more time, give them that time and return for more discussion.

7. How to respond when the family is still uncertain.
Objective: Give the family time and space to think; if the clinician truly believes in the benefits of an autopsy, try to gently convey that and see if the family is willing to reconsider.

8. How to respond when the family declines to give consent.
Objective: Respect the family's decision; help them with the next steps.

9. How to respond when the family agrees to give consent.
Objective: Help them go through the consent form with explanations and make sure the family understands everything.

< Filming Order >

- Great approach > Neutral approach > Poor approach
- Natural flow through sections 1 ~ 6 with short pauses between each section for easy editing > (CUT) > 7 > (CUT) > 8
- Duration for each conversation: 15-20min-ish

< Character description >

A. Patient (dead)

- Jason Lee, Male, 40s
- Came in for an *appendectomy (ruptured before he arrived)*. A short stay turned into a few days of hospitalization. He stayed in the regular hospital ward where they have no monitors.
- Unexpectedly died today, cause not clear. He was found dead in his bed.

B. Patient's spouse

- Helen Lee, Female, 40s.
- would have seen the patient + have spent time with him
- Earlier today, heard her husband died.
- Approached by a different clinician* during the scenario, asking for an autopsy consent.

C. Clinician

- Approaching the family to request an autopsy consent.
- Believes that an autopsy can be beneficial.

< Synopsis & Setting >

A. Synopsis

- Male patient in their 40s suddenly died after few days of hospitalization. The sad news was shared with the spouse earlier today. The clinician stepped out and a different clinician is approaching the spouse to ask for an autopsy consent.
- The clinician believes an autopsy can benefit the family, but the family is emotional and confused.

B. Setting

- Office setting in the hospital
- Clinician and family masked and sitting > 6 ft apart due to COVID-19 safety precautions.

< Script – Great approach >

1. Initiating the conversation

Clinician: (Family must feel profound grief. Let's talk in a soft voice. Show sympathy.)
Hello Mrs. Lee. My name is Dr. Fullerton and I am a member of the team who was caring for your husband. "I am so sorry for your loss. I understand that your husband's death was very sudden and unexpected. While the death of any family member is difficult, when it is sudden it is so difficult to understand. (Pause to get reaction from family member.)
We would like to offer you a way to explore the cause of death.

Family: (emotional, confused.)
Still, interested in finding out what the option is.

Ex: Like…like what? I… don't understand… we came in for an appendectomy…. then he suddenly died, what happened? Why is this happening?

Clinician: At Johns Hopkins Hospital, all families have the right to an autopsy for a patient who dies at JHH. Would you like to discuss this for your husband?"

2. Explaining how an autopsy can be beneficial.

Family: (continued from 1. / emotional, confused.)

Unsure about the autopsy or why it would be helpful.

Ex: Why….why would I want an autopsy? How is that going to help?

Clinician: (Let's inform them about all the benefits.)

"It is still unclear why your husband died but an autopsy will help us understand why. An autopsy can be beneficial for *you*, your loved one, and your family. The procedure can help you understand the cause of death, discover any familial diseases which can be important for other family members to know. (short pause)

The autopsy can help other families and patients as well. The knowledge we gain will help improve medical treatment for other patients with the same condition. Many families have mentioned that the autopsy results of their loved ones helped them find closure."

3. Listening and understand where the family stands.

Family: (emotional, confused.)

Still unsure about the autopsy.

But… I…

Clinician: (Not assuming anything. Gauge the family's comfort level.)

"I can help answer any questions or concerns you may have at this point. If you are uncertain, would you allow me to explain more about the procedure? Pause to get assent from the family member. You do not have to make a decision right now."

4. How to respond when the family asks questions about the autopsy procedure.

Family: (emotional, confused.)

Slowly showing interest in the autopsy.

I don't know much about….an autopsy….what's going to happen? Is it going to be something like CSI?

Clinician: (The family has a lot to process. Ask how much detail the family would like to know.) "Your husband's autopsy would be supervised by a doctor called a pathologist, then his body will be transferred to the funeral home. The autopsy report can be mailed to you if you wish to receive it. Would you like to know more about the autopsy procedure? I can guide you through, but please let me know at any point, if any of the details cause you discomfort." + mention the body is treated with respect.

5. What if the family has requests due to religious beliefs or other reasons.

Family: …I mean…will we see scars?... on his face?... (concerned)… the funeral… what am I going to do about the funeral…everyone will want an open casket.

Clinician: (I am certain that the family can make special requests.)

"The autopsy will not affect an open casket viewing. The face, arms, and legs will not be touched unless given permission. Additionally, families have the right to limit the extent of the examination due to religious or any other personal reasons. For example, the autopsy may only include the body or not involve the brain. Of course, limitations to the examination may decrease the information obtained from the autopsy. If you do decide to request an autopsy and wish to make a special request, I can help you leave a request on the consent form to accommodate them."

6. How to ask for final autopsy consent to an emotional family.

Clinician: what are your thoughts about the autopsy?

Family: I….we….(sigh)…well….(seems emotional).

Clinician: (Give time and space. Come back once they are ready.)

"I sense you want more time to think about it. I can leave and come back later. Would you prefer (like) that?"

Family: yes…I would like that…

7. How to respond when the family is still uncertain.

Family: I thought about it and I am not sure if we really want an autopsy.

Clinician: (I really think an autopsy will be beneficial. But the final decision is the family's)

"Thank you for letting us know your decision. If I may, I still believe an autopsy could be beneficial for you and your family. The autopsy will need to be completed before 72 hours after death, but you still have time to reconsider if you wish to take advantage of this service. I understand this is a hard decision to make. I want to reiterate; the final decision is yours and I will be available if you do decide to reconsider."

8. How to respond when the family declines.

Family: I thought about it and we don't want an autopsy.

Clinician: Thank you, I respect your decision.

(Show empathy and explain what to do next. Maybe suggest making funeral arrangements. If the family already made funeral arrangements, help them contact the main admitting office.)

9. How to respond when the family agrees to give consent.

Family: I thought about it… and…I think we should have an autopsy.

Clinician: (Help them go through the consent form with explanations.)

"Thank you for letting us know your decision. I will help you go through and complete the autopsy consent form. Please let me know if you have any questions or concerns at any point."

(clinician shows the consent form to the family

< Script - Neutral >

1. Initiating the conversation

Clinician: (This is a simple task: gently ask if the family is interested in an autopsy.)

"I am so sorry for your loss. Your husband's death was very sudden. Would you be interested in exploring the cause of your husband's death - perhaps through an autopsy?

Family: (emotional, slightly surprised.)

Interested in finding out the cause of death, but *slightly surprised* by the word 'autopsy'.

Ex: An autopsy? Like what they do in CSI?

2. Explaining how an autopsy can be beneficial.

Family: (continued from 1. emotional, confused.)

Unsure about the autopsy or why it would be helpful.

Ex: How is….this….autopsy going to help? My husband came in for a liver biopsy, then he died. This won't bring him back.

Clinician: (This can help figure out cause of death.)

"It is still unclear why your husband died. An autopsy can help us to figure out the cause of death."

3. Listening and understand where the family stands.

Family: (emotional, confused.)

Still unsure about the autopsy.

But….

Clinician: (Assume the family is not informed but talks quickly.)

"If it helps, I could quickly go through some necessary information regarding the autopsy. The information I give you is all here on the consent form if you wish to review it later."

(Narration: the clinician gave information based on the consent form.)

4. How to respond when the family asks questions about the autopsy procedure.

Family: (emotional, thinking maybe an autopsy might help but still unsure)

I don't know much about….an autopsy.…what will happen?

Neutral: (Let's give necessary information and ask if they have questions.)

"Your husband's autopsy will be performed here at Johns Hopkins hospital. The pathologist who does it will cut open his body and examine his organs.

Once it's done, his body will be transferred to the funeral home. The autopsy report will be available to you if you wish to receive it. Do you have any questions?"

5. What if the family has requests due to religious beliefs or other reasons.

Family: …I mean…will we see scars?... on his face?... (concerned)… the funeral… what am I going to do about the funeral…everyone will want an open casket…

Clinician: (I am not sure of the answer, but I know who to ask.)

"I will have to check that with the pathologists. I will also check if you can limit the areas of the body. Would it be okay if I briefly look up their number and contact them?"

Family: … yeah…

6. How to ask for final autopsy consent to an emotional family.

Clinician: Are you ready to decide?

Family: I….we….(sigh)…well….(seems emotional).

Neutral: (Suggest reviewing information.)

"I understand that there is a lot of information to take in. Please take your time to decide. Please let me know if you would you like to take a look at the consent form again."

7. How to respond when the family is still uncertain.

Family: I thought about it and I am not sure if we really want an autopsy.

Clinician: (I really think an autopsy will be beneficial. Would the family reconsider?)

"I see. I still think that an autopsy will be very beneficial. Would it be possible for you take some more time to reconsider?"

8. How to respond when the family declines.

Family: I thought about it and we don't want an autopsy.

Clinician: Thank you, I respect your decision.

(Explain what to do next. Maybe suggest making funeral arrangements. If the family already made funeral arrangements, help them contact the main admitting office.)

9. How to respond when the family agrees to give consent.

Family: Yes. I think we want an autopsy.

Neutral: (Go through the consent form.)

"Thank you. Now I will help you quickly complete the autopsy consent form."

(clinician shows the consent form to the family)

< Script - Poor >

1. Initiating the conversation

Clinician: (The family must be tired. Make it quick and fast.)

Hello. I am sorry, what is your name again? I came to ask if you might want an autopsy."

Family: (emotional, surprised, upset.)

Startled by the word 'autopsy'. Unsure why an autopsy is brought up in the first place.

Ex: What!? Why would I want an autopsy?

2. Explaining how an autopsy can be beneficial.

Family: (continued from 1. / emotional, confused.)

Unsure about the autopsy or why it would be helpful.

Ex: How is an autopsy going to help? My husband came in for a liver biopsy, then he suddenly died Clinician: (It is just something we offer to all families.)

"An autopsy is something we offer to all families. The information may be beneficial to you in finding out why your husband died."

3. Listening and understand where the family stands.

Family: (emotional, confused.)

Still unsure about the autopsy.

I….

Clinician: (Assume the family is already informed, wants to save time.)

"I imagine you already have an idea of what an autopsy is, (how? From watching television programs like CSI?) but I'll answer any questions, if you have any."

Clinician then checking messages on phone without explaining this to the family member

4. How to respond when the family asks questions about the autopsy procedure.

Family: I actually don't know much about….an autopsy…what will happen?

Clinician: (It is important that the family knows the details and medical terms.)

"The autopsy will start with an opened Y or U-shaped incision down the chest. (Hand gesture showing the incision location)

Fluids and tissue will be collected, organs may be removed, and the pathologists will also check the brain and spinal cord for thorough observation."

Family: (shocked at the hand gesture, listens to everything till the end but shocked.)

(highly possible the family will end the conversation here, but we want it to go on.)

5. What if the family has requests due to religious beliefs or other reasons.

Family: …I mean…will we see scars?... on his face?... (concerned)… the funeral… what am I going to do about the funeral…everyone will want an open casket.. can you not touch the face?

Clinician: (It is unlikely that the family can make special request.)

"I am not sure if the autopsy will affect an open casket funeral and unfortunately, autopsies are standardized procedures. So, I believe it will be hard to make any special requests."

6. How to ask for final autopsy consent to an emotional family.

Clinician: Are you ready to decide?

Family: I….we….(sigh)…well….(seems emotional).

Clinician: (The family must be tired. Get an answer quick and let them rest.)

"If you could give us your final decision right now, that would be very helpful. Everything else will be quick and we will let you rest. You must be exhausted."

7. How to respond when the family is still uncertain.

Family: I thought about it and I am not sure if we really want an autopsy.

Clinician: (I really think an autopsy will be beneficial. They must reconsider.)

"In my opinion, an autopsy will be very beneficial. I can't think of a reason why you should not have an autopsy for your husband."

8. How to respond when the family declines.

Family: I thought about it and we don't want an autopsy.

Clinician: (I really think an autopsy will be beneficial. They must reconsider.)

"I am so sorry, but in my opinion, an autopsy will be very beneficial. I really think you should reconsider."

9. How to respond when the family agrees to give consent.

Family: Okay. I think we want an autopsy.

Clinician: (Thank the family, get their signature and leave.)

"Okay. This is the consent form. I believe we already discussed everything, so I just need your signature and I will take care of the rest for you."
(clinician hands over the clipboard)

Appendix E: Subtitles and narration for the interactive simulation.

< *Subtitles and Narrations* >
DOC: clinician, SP: Standardized Patient

Narration: This simulation provides interactive training for asking an autopsy consent. We will follow Dr. Fullerton, a clinician at the Johns Hopkins Hospital, tasked to request an autopsy consent from Mr. Lee's wife. Mr. Lee came in for an appendectomy and has unexpectedly died. Mrs. Lee was notified a few hours ago, earlier today. How should Dr. Fullerton approach Mrs. Lee? Choose the best option to initiate or continue the conversation throughout the simulation.

< 1. Initiating the conversation >

1. Review Mr. Lee's chart prior to entering the room.
Slowly introduce the idea of autopsy. (great)

2. Review Mr. Lee's chart prior to entering the room.
Clearly address the autopsy and save effort and time. (Neutral)

3. It is most important that Mrs. Lee hears about the autopsy.
Focus on saving effort and time. (Poor)

Great #1

DOC: Hello, Ms. Lee. I am Dr. Fullerton; I am one of the doctors here at Hopkins and I am so very sorry about your husband's death.

SP: I mean, I don't understand what happened. He was here for the appendectomy. I mean, I spoke to him yesterday and he seemed fine and, now they've just, I mean he's died. And I don't know what to think, I don't know what to feel, I haven't even told our kids, I don't understand what's happened.

DOC: I am so very sorry that we're having to have this conversation. I can't imagine how difficult this must be.

SP: (sighs)

DOC: I think any death of a family member is so difficult, but especially when it is so unexpected. So, one of the things I did wanted to talk with you about is to maybe talk through ways that we could try to get more answers and try to understand why Mr. Lee died.

SP: Well, I mean, he was here because of the appendectomy, so I figure it was probably something that went wrong with the surgery. But you are telling me…I'm not following you.

DOC: Well, I don't think anyone really knows why Mr. Lee died and so I wanted to suggest to you, or present to you, the option of getting an autopsy. All families who have had loved ones die at our hospital has the right to get an autopsy.

> < *Feedback page* >
> Narration: Dr. Fullerton made sure to check the charts and correctly addressed Mrs. Lee and properly introduced herself. Mrs. Lee was still in shock but when Dr. Fullerton showed respect and empathy, Mrs. Lee was able to slowly open up to Dr. Fullerton. Dr. Fullerton understood that the word 'autopsy' could be alarming. She slowly eased into the concept of 'autopsy' and made sure Mrs. Lee understood it was her right to request an autopsy.

Neutral #1

DOC: Hello, Ms. Lee. I am Dr. Fullerton. I am one of the physicians here and I am here to speak with you about an autopsy for your husband.

> < *Feedback page* >
> Narration: Dr. Fullerton made sure to check the charts and correctly addressed Mrs. Lee and properly introduced herself. She brought up the autopsy as soon as possible to save everyone's time. However, she did not consider that Mrs. Lee was still in shock and hearing the word 'autopsy' abruptly could alarm her. Dr. Fullerton also forgot to tell Mrs. Lee, that all families who have had loved ones die at the Johns Hopkins Hospital have the right to request an autopsy.

Poor #1
DOC: Hello. I'm sorry, what is your name? How should I refer to you?

SP: Um… you don't even know who I am? My husband just died and they sent you in here…to talk to me.

DOC: I know.

SP: I don't even…who are you?

DOC: I am one of the doctors that works here and I'm in here to talk with you about getting consent for an autopsy for your husband.

> < *Feedback page* >
> Narration: Dr. Fullerton was in a hurry to help Mrs. Lee and forgot to check the charts. Dr. Fullerton did not know how to address Mrs. Lee and also forgot to properly introduce herself, which Mrs. Lee found disrespectful. She also brought up autopsy abruptly and should have also told Mrs. Lee, that all families who have had loved ones die at the Johns Hopkins Hospital has the right to request an autopsy.
>
> > < *Key point summary* >
> > When initiating the conversation…
> > - Provide emotional support.
> > - Introduce yourself and properly address the family member.
> > - Mention all families who have had loved ones die JHH have the right to request an autopsy

Narration: Dr. Fullerton wanted Mrs. Lee to understand the benefits of an autopsy. An autopsy can…

> **< 2. Explaining how an autopsy can be beneficial >**
>
> 1. Help find the cause of death, discover any unknown familial diseases, and help improve treatments for other patients suffering from similar conditions. (great)
>
> 2. Help find the cause of death. (Poor)
>
> 3. Help find the cause of death and discover any unknown familial diseases. (Neutral)

Great #2
SP: So, wait a minute. When you said autopsy, I thought it was something like…autopsies were done when there was like a crime…you know on somebody or…are you saying something might have happened here to him that you have to investigate what happened?

DOC: I understand why you might think that. That's what happens on television a lot that they link it with a crime. No, we do not think that any crime was committed. But an autopsy can really help a family to get more understanding. It can help to perhaps get an answer of why Mr. Lee died. It can help if Mr. Lee had some medical condition of which you or he were unaware, that might be relevant to other family members and sometimes the results of the autopsy can help other families, whose love one has suffered from a similar condition to kind of reach closure with it.

SP: So, you're saying that you want to find out what happened.

DOC: We would like to. I think we all feel that's important and I wanted to know if you and your family might find that important also.

SP: (sighs) I mean, I know that I haven't even told our kids, so I don't even know what to tell them what happened and you're telling me to do this would find out what happened, but I mean… is it going to affect what he looks like when he is buried? Is it going to affect…I have to find out if it's going to affect his religion? I mean, that's a lot to ask right now. I do want to find out what happened, but there's so many things that I need to check first.

> < *Feedback page* >
> Narration: Dr. Fullerton was aware of all the important benefits of an autopsy, which would help Mrs. Lee and her family.

Neutral #2

SP: An autopsy for my husband? I… So, wait a minute, I just found out that my husband has died…here in the hospital and now you want to talk to me about… I mean what…did something happen that, you feel like there was a crime or something committed? Isn't that what an autopsy is?

DOC: No not at all and I am glad that you mentioned that. The reason that I wanted to bring up the autopsy is your husband's death was so unexpected and an autopsy can help us, and also help you as his family, to better understand why he may have died.

SP: I figure because he was here for this appendix thing and he seemed to be doing fine, but I figure there was because something went wrong with the appendix… and that's why… that's why he's gone.

DOC: Yeah, we don't know that. That's one of the reasons to do the autopsy to better examine that. We are also thinking, could this have been due to some medical condition that he might have had that you and he were unaware of. So, this autopsy could help you to understand that, could help your family in case there are some family conditions that it would identify, and also might help other families whose loved ones have suffered from a similar problem.

SP: I mean… is it even…I don't know. It just feels weird and not really appropriate to even talk about this right now.

< *Feedback page* >
Narration: Dr. Fullerton was aware of the important benefits of an autopsy, which would help Mrs. Lee and her family. However, she forgot that an autopsy can also help improve treatment for other patients suffering with the same condition. Being part of something larger can often help families reach closure.

Poor #2

SP: Okay, my husband just died… and you're telling me that you are here to ask me to have him cut? I…don't even understand. An autopsy I thought was something that you know if somebody was… a victim of a crime or something like that happen. Are you telling me that somebody did something to my husband?

DOC: No~ No~ not at all. No. An autopsy is really to try to get to the bottom of why he may have died so unexpectedly. So, it would give us information, it would give you information about why he may have died. It might identify reasons that are important for your family to know because there could be a family condition. It might also help other families ~~.

SP: I mean…that's… all well and great, but I'm not really concerned about other families right now. I'm just trying to understand and process that's happened. My husband's dead and you're here telling or asking me that you want to cut him and figure out what happened? This is a lot.

< *Feedback page* >
Narration: Dr. Fullerton was aware that an autopsy can help find the cause of death. However, she forgot that an autopsy can also help discover unknown familial diseases and improve treatment for other patients suffering with the same condition. An autopsy can be beneficial to both Mr. Lee's family and medical advancement.

< *Key point summary* >
Autopsies can help…
- Exploring the cause of death
- Discover unknown familial diseases
- Improve treatment for other patients suffering with the same condition

Narration: To help Mrs. Lee make her decision, Dr. Fullerton wants to give Mrs. Lee more information about the autopsy. From Mrs. Lee's previous response, Dr. Fullerton realized…

< 3. Listen and understand where the family stands >

1. It is most important at this moment to inform Mrs. Lee about the autopsy process and help her stay focused on the consent. (Poor)

2. Mrs. Lee might be overwhelmed. Listen to what Mrs. Lee is saying and figure out if she is ready and willing to receive more information. (great)

3. It would be beneficial for Mrs. Lee to be informed about the autopsy, but maybe Mrs. Lee also needs some more time? (Neutral)

Great #3
DOC: Of course, those are all really good points and really good questions. If I could, maybe I could just tell you a little bit about an autopsy and then I am happy to answer any other questions you have.

SP: Um…yes. I mean, I can't guarantee that I'll hear everything. Like I said, I am in shock.

DOC: Yes. Of course.

SP: I'm numb, I'm confused, but I guess whatever you can tell me will be helpful.

DOC: Of course, and I'm happy to tell you again later, if need be, if we need to repeat anything.

SP: Yeah…

Narration: Dr. Fullerton provided information about the autopsy gradually, including the fact that the autopsy needed to be done before 72 hrs after Mr. Lee's death. Dr. Fullerton was mindful to give some time for Mrs. Lee to process each portion of new information and repeated them when Mrs. Lee seemed confused.

> < *Feedback page* >
> Narration: Mrs. Lee clearly seemed overwhelmed with the situation. Dr. Fullerton listened to Mrs. Lee and understood her emotional state. Dr. Fullerton made sure Mrs. Lee was willing to receive more information and offered to repeat the information later if needed.

Neutral #3
DOC: Well…unfortunately there is some time limitations. The decision has to be made within 72 hrs. Well, not the decision but the actual procedure has to be done within 72 hrs of his death. I am happy to offer you more time. It sounds like maybe you need that. But it is something that we should probably try to discuss today if at all possible.

SP: (exasperates) I…I can't discuss this today. I have to tell our kids that our husband just died and I have to tell his family, I have to make arrangements… You are telling me that it has to done in 72 hrs, I mean, we need 72 hrs just to figure out how to make these arrangements, to have him buried. I…I can't do this right now.
DOC: Yeah, well…I am happy to give you more time. So you know the autopsy would take place before the body goes to the funeral home.

SP: (frustrated sigh) I have to find a funeral home. I mean, I don't even know how to tell our kids what just happened. I don't know what to tell them just happened.

DOC: Well, we have staff here that could help with that. I am happy to call the social workers or Chaplins here can definitely talk with you and also have your family come here, so that we can all talk about it together if you think that would be helpful.

SP: Some of our kids are…they are not even in the state. This is… I can't even figure this out by myself right now.

DOC: Well, it sounds to me like you need more time. So would that be helpful if I give you more time?

SP: (frustrated voice) I…I mean yeah. my gosh. Yeah, I need more time. I can't even think straight. I don't even know where to begin or what to do and asking permission to have my husband's body cut opened is…kind of like the least of the things I want to think about right now.

DOC: I understand. Would it be okay if I came back in a little while to talk with you again?

SP: Yeah. That's… that's fine.

Narration: Dr. Fullerton told Mrs. Lee she would be back in an hour. After making sure Mrs. Lee was ready, Dr. Fullerton provided information about the autopsy.

> < *Feedback page* >
> Narration: Dr. Fullerton tried to provide important information to Mrs. Lee. However, Mrs. Lee was already overwhelmed with the situation and additional information just made her more uncomfortable. Dr. Fullerton realized Mrs. Lee's discomfort and gave her some time to process.

Poor #3

Doc: Yeah. Please know I don't want to cut him. I just want to find out what is happening. Why is this happening.

SP: (sigh) Well..

Doc: Would it help if I gave you more information about what happens during an autopsy?

SP: Well.. I mean… were you even with my husband? I'm still not sure who you are…or…

Doc: Yeah. I was not with your husband, I'm sorry. But I am the person they send in to talk about the autopsy and see what your feeling are about that.

SP: I haven't even talked to anybody who's told me what happened. If my husband said anything, if he was in pain…

Doc: I'm sorry that's terrible. We can have someone come in; maybe a nurse or maybe one of the doctors from the team could come speak with you a little bit more about that.

SP: It's also really shocking that you're here just kind of asking me this and… I haven't told my kids anything. I don't know how to respond to this…

Narration: Dr. Fullerton told Mrs. Lee she would be back in an hour. After making sure Mrs. Lee was ready, Dr. Fullerton provided information about the autopsy, including the fact that the autopsy needed to be done before 72 hrs after Mr. Lee's death.

< *Feedback page* >
Narration: It is important to keep Mrs. Lee informed. However, Mrs. Lee was already overwhelmed with the situation and additional information just made her more uncomfortable. Dr. Fullerton eventually was able to realize Mrs. Lee's discomfort and gave her some time to process.

< *Key point summary* >
When talking to the Family…
- Read the room
- Gauge the family's comfort level.
- Do not assume prior knowledge about an autopsy.
- Inform autopsies need to be done within 72 hrs after death
- Introduce other helpful resources (ex. social workers or religious representatives).

Narration: As Dr. Fullerton continued to provide information, Mrs. Lee listened and asked a question about what would happen during the autopsy. Dr. Fullerton proceeded to…

< 4. Responding to questions about the autopsy procedure >

1. Explain the autopsy process. Mrs. Lee's question was specifically about the process, so summarize the steps for an autopsy and try not to add any other information. (Neutral)

2. Explain the autopsy process and briefly inform Mrs. Lee about the examined structures. It is important that Mrs. Lee knows every detail about what happens to her husband's body. Utilizing hand gestures can help Mrs. Lee visually understand the affected area. (Poor)

3. Explain the autopsy process, involved personnel, and how the body is treated. Medical details were left out for now, because Mrs. Lee may become uncomfortable or upset because of the imagery. (Great)

Great #4
DOC: The autopsy is supervised by a doctor here called a pathologist and different parts of your husband's body are examined to try to find the cause of death. I do want you to know that the patient's body is always treated with the utmost respect and an autopsy is done in a very clean and sanitary way.

SP: Well, I appreciate that. You want to find out or help us find out. I mean, does it… do we have to pay for it? What is going to happen?

DOC: No. There is no charge to the family. And you reminded me of a question you have asked earlier that I don't think I answered, whether this would affect an open casket or how he looked and (cut*)

< Feedback page >
Narration: Medical details or vivid imagery about the autopsy can upset families. It is not too late to elaborate once the family willingly asks for more clear descriptions about the process and affected body structures. Dr. Fullerton understood that families will appreciate knowing who will conduct the autopsy and that their loved one will be treated with respect.

Neutral #4
SP: So…I mean, you're asking to perform an autopsy on my husband. I mean, I don't even know what that involves. What does that even like?

DOC: So, they open up his body and they examine his organs to look to see if they can determine what the problem was and what caused his death.

SP: ….Okay

< Feedback page >
Narration: Dr. Fullerton answered Mrs. Lee's question with a concise summery of the process. Mrs. Lee got an answer to her question. However, she still does not know who will conduct the autopsy, how their loved one will be treated during the autopsy, or if there is a fee. These details are frequently concerns for families and should be included.

Poor #4
Doc: So, during an autopsy, what is done, is that they make an incision in your husband's chest kind of like this and then they will take out the organs and look at them and the different body fluids to see if they can determine why, he may have died.

SP: Okay, well, that's…really… detailed description.

> < *Feedback page* >
> Narration: Unfortunately, Dr. Fullerton's use of hand gestures made Mrs. Lee uncomfortable. Medical details or vivid imagery about the autopsy can upset families. It is not too late to elaborate once the family willingly asks for more clear descriptions about the process and affected body structures. Perhaps Mrs. Lee would have appreciated other information such as who will conduct the autopsy, how their loved one will be treated with respect, or if there is a fee.
>
> > < *Key point summary* >
> > When giving the family information,
> > - Try not to put all the burden of asking questions on the family.
> > - Don't give discomforting details without checking if it's okay with them.
> > - Listen and observe non-verbal cues to gauge how to react.
> > - Do not use medical jargon.

Narration: After learning about the autopsy process, Mrs. Lee became worried about the affected areas and how the autopsy may affect an open casket viewing. Dr. Fullerton…

< 5. Open casket viewing and special requests due to personal reasons >

1. Knows who to contact for such information and asks Mrs. Lee if she can use her own phone to contact staff who may have the answer. (Neutral)

2. Knows who to contact for such information and shows Mrs. Lee a mobile device, signaling that she can contact staff to help Mrs. Lee as soon as possible. (Poor)

3. Readily tells Mrs. Lee that the autopsy will not affect the open casket viewing and that she can also ask for a special request to limit the autopsy. (Great)

Great #5

SP: I mean, do they do something to his face or his head? They don't do anything like that or…?

DOC: His face is not touched and if you do agree to have his brain examined, that is done in a way that it's not obvious when he is in the casket. (*paste) *If Mr. Lee has on a shirt or a suit, you would not be able to tell in the casket that he had had the autopsy.*

Narration: Dr. Fullerton also mentions that special requests can be made through the consent form to limit the autopsy if Mrs. Lee wishes to do so.

SP: Um…yeah. I do want to find out what happened so… I need to talk to my kids for a few minutes but I think maybe they will agree… yeah…

< *Feedback page* >

Narration: Dr. Fullerton was aware that the autopsy will not affect the open casket viewing and that Mrs. Lee can also ask for a special request to limit the autopsy through the consent form.

Neutral #5

SP: I mean, we would want things like an opened casket, I mean, would they see scars from something like that?

DOC: You know, I'm not really sure. I can call someone to find that out. Would that be okay with you?

SP: Wait a minute, I've got a whole bunch of other questions. I mean, religiously, I have to find out and figure out if this is even allowed for my husband. I don't even know anything about that.

DOC: Yeah. Unfortunately, I don't know too much about that either, so again, I am happy to call one of our Chaplains, they can talk with you and give you a bit more information about that if that's important to you.

SP: I mean, is there anybody here that can help me with like, how would I even… no matter what I decide, how do I move my husband from here to a funeral home. I mean, I'm in shock. I don't know what to do.

DOC: Yeah…I can see that… We do have staff that can help with this so let me call one of the social workers and they can explain some of these next steps to you. Again, my job was just to talk to you about the autopsy.

Narration: With Mrs. Lee's permission, Dr. Fullerton was able to contact a pathologist who had the answers to Mrs. Lee's question.

> < *Feedback page* >
> Narration: Dr. Fullerton was not aware that the autopsy will not affect the open casket viewing and that Mrs. Lee can also ask for a special request through the consent form to limit the autopsy. Fortunately, Dr. Fullerton knew who to contact for information. She took the time to ask Mrs. Lee if she could use her phone, avoiding being disrespectful. However, Mrs. Lee would have appreciated more if it was Dr. Fullerton who had the answers to her questions.

Poor #5

SP: I mean… when you do something like that…I mean, I got to have a funeral for him. Will the scars be seen? Will it upset my kids?

Doc: You know, that's a great question. I honestly don't know the answer to that. Would it be okay if I call someone to ask them?

SP: Wait, wait a minute! Excuse me. I thought that you were here to answer these kinds of questions and give me this kind of information. I might have other things that I might want to ask you.

Doc: Well, you know, we… we've never really been trained in this, so my job was really to just get you to sign the consent…so…

SP: (dumbfounded) My husband just died and you're telling me that you haven't even been trained to do this… I am really a little perturbed that you are even in here talking to me right now. I think I'm a little bit more concerned with maybe calling somebody who does know how to talk to me about this.

Doc: Well…I can see if anyone else is available… I don't know that anyone is…

SP: You know what, yeah… I think I would really appreciate that because I'm not… Honestly, you're actually making me a little bit more upset. I don't want to feel rushed. (sighs) I don't know…

< *Feedback page* >
Narration: Dr. Fullerton was not aware that the autopsy will not affect the open casket viewing and that Mrs. Lee can also ask for a special request through the consent form to limit the autopsy.

Dr. Fullerton knew who to contact for information, but forgot to ask Mrs. Lee if she could use her phone, which may have seemed disrespectful. Dr. Fullerton tried to defend her lack of information with the fact that she was never trained to ask for autopsies. However, that made Mrs. Lee even more uncomfortable.

< *Key point summary* >
Be aware that…
- Families may have religious / personal reasons to limit the autopsy.
- Requests can be made through the consent form.

When searching / contacting resources…
- Ask if it's okay to use your mobile device.

Narration: Time has passed and Dr. Fullerton wishes to receive Mrs. Lee's final decision. However, Mrs. Lee is uncertain and overwhelmed by all the information she just received. Dr. Fullerton decides to…

< 6. Asking for final decision >

1. Focus on obtaining the final decision from Mrs. Lee. (Poor)

2. Give Mrs. Lee some time to think. Suggest representatives or resources that could help Mrs. Lee decide. (Great)

3. Give Mrs. Lee some time to think. If Mrs. Lee asks for help, get staff that could help her. (Neutral)

Great #6
DOC: Okay. Of course. Let me give you some time and I am happy to come back and talk with you in a little bit. In the meantime, can I get you any water or anything to eat or anything else?

SP: (sighs) Just some water…some… I don't know…and a few minutes.

DOC: Of course.

SP: …to make some phone calls…yeah.

DOC: Okay. I'll stop back in a little bit and please let us know if there is anything else we can do to help support you and your family.

SP: um… yeah… if you have somebody who can talk to me about arrangements… I don't even know where to begin.

DOC: Absolutely. So, our social worker can be very helpful with that as well as can the Chaplain, so I would be happy to call them and ask them to come in and they will be happy to assist you and I am happy to help you in any way I can also.

> < *Feedback page* >
> Narration: Dr. Fullerton noticed that Mrs. Lee seemed overwhelmed. Dr. Fullerton gave Mrs. Lee time and space to think. Religious representatives or social workers could help Mrs. Lee process and make her final decision.

Neutral #6
So, I'll be back in a little bit. Would it help if I gave you a little bit more time to think about this? Maybe for your family?

SP: Yeah… I just need some information. I need, you know I need some help.

DOC: Yeah…I see that. Okay. We'll get that for you.

> < *Feedback page* >
> Narration: Dr. Fullerton noticed that Mrs. Lee seemed overwhelmed. Dr. Fullerton gave Mrs. Lee time and space to think and searched for other staff that may help Mrs. Lee.
>
> Mrs. Lee may not be aware of religious representatives or social workers at the hospital. Perhaps informing Mrs. Lee of the options of help she can receive can help Mrs. Lee seek the right type of help she needs.

Poor #6
SP: So… I… (sign) I mean, this has not been very helpful right now. I'm in shock. Haven't told our kids what's happened and I just don't know what to do. I need some time with this. I really do.

Doc: Okay. I understand. I really do think though, that getting an autopsy is the right thing to do.

SP: (sighs)

Doc: I think that would really help you and your family and just so you know, you have to make a decision fairly soon, so I'll step out and I'll check back in with you…

SP: Wait, no no no! What I'm saying is, and I don't feel that you're listening to me, is that I need some time! To process, that my husband has just died and you're asking me to have him cut to see what happened, but I need to move pass just this thing that just happened. You're here. I can't get any answers from you and I need help. You're asking me to do this big thing right now and I just..I can't say yes or no right now. I need some time.

Doc: Okay. Would you let me know when you want me to come back in?

SP: (frustrated) You know what, maybe there's somebody else that can help me with this because I feel like you're not LISTENING to what I'm saying and I'm angry and I'm upset and I'm numb, and I'm everything! I just…I'm saying I don't know what to do right now. I'm not making the decision. Please stop asking me.

Doc: Okay.

> < *Feedback page* >
> Narration: Mrs. Lee was overwhelmed and needed some time and space to collect her thoughts. Though a professional opinion can be useful, Dr. Fullerton did not read the cues from Mrs. Lee indicating that she was not prepared to make a final decision at this point. Mrs. Lee may not be aware of religious representatives or social workers at the hospital. Perhaps informing Mrs. Lee of the options of help she can receive can help Mrs. Lee seek the right type of help she needs.
>
> > < *Key point summary* >
> > When the family needs to think more…
> > - Give time and space to the family.
> > - Return later for further discussion.
> >
> > Meanwhile, keep in mind that…
> > - Autopsies need to happen within 72 hrs after death
> > - Clinician can introduce helpful resources (ex. Social worker, religious representative)

Narration: Mrs. Lee has firmly decided to NOT have an autopsy for Mr. Lee. Dr. Fullerton responds to Mrs. Lee's decision by…

> **< 7. How to respond when the family declines >**
>
> 1. Respecting Mrs. Lee's decision. Perhaps Mrs. Lee would like to know what the next step is to receive some help. (Great)
>
> 2. Respecting Mrs. Lee's decision. Hospital staff can help Mrs. Lee with the next steps. (Neutral)
>
> 3. Respecting Mrs. Lee's decision, but hinting that Mrs. Lee might want to reconsider. After all, the results from the autopsy will benefit Mrs. Lee and her family. (Poor)

Great #7

SP: I have talked to my family, our family…my kids are not… For one thing, they are broken hearted, I am broken hearted. We don't want this. We don't want my husband, their father cut open…we just…his family doesn't want it…no. we decided we do not want an autopsy. We just want my husband and we just want to bury him, let him be in peace, and just, I don't know, try to get through this.

DOC: I understand and thank you for sharing your decision with me. The next steps would be for us to contact a funeral home and both I and we have other staff here who can help with that.

SP: Yes. Thank you. I…my mind is just so…frazzled, I can't even think about what to do, so yes, that would be very helpful.

DOC: Yes, of course. Can I get you anything else in the meantime? Any water or anything to eat?

SP: No, thank you.

DOC: Okay. Again, I am so very sorry.

SP: Thanks…

> < *Feedback page* >
> Narration: If Mrs. Lee seemed uncertain about declining, Dr. Fullerton might have gently asked Mrs. Lee to reconsider and discussed the benefits of an autopsy. However, Mrs. Lee's decision was firm and Dr. Fullerton fully respected Mrs. Lee's decision. Often families will not know what to do next and Mrs. Lee did seem confused. Dr. Fullerton stayed supportive and informed Mrs. Lee that making arrangements for the funeral home would be the next step and that she could receive help from the hospital.

Neutral #7

SP: I have… You know, I don't see how this is going to help anything. If anything, I think it's going to make everything worse. On top of my husband passing away so suddenly, I don't think I want to do this. I don't think it would good for my family and I don't think it's what my husband would want at all. So, I just need to make the arrangements to have him buried and transported, so that he can just rest in peace, so we can grieve and…no I don't want to do this. I am sorry.

DOC: No. I understand and I absolutely respect your decision. May I call some staff that can help with some of the next steps and the next arrangement?

SP: Yeah, that would be helpful. Yes.

DOC: Okay, let me go ahead and do that. We'll be back in to talk with you.

SP: Alright, thanks.

> < *Feedback page* >
> Narration: Narration: If Mrs. Lee seemed uncertain about declining, Dr. Fullerton might have gently asked Mrs. Lee to reconsider and discussed the benefits of an autopsy. However, Mrs. Lee's decision was firm and Dr. Fullerton fully respected Mrs. Lee's decision. Often families will not know what to do next and perhaps Mrs. Lee would have appreciated if Dr. Fullerton had let her know that the next step would be making arrangements for the funeral.

Poor #7

SP: So… I've told my kids….you know… while you were out that their father is gone. I hear what you are saying about…wanting to do this autopsy on him, but the truth is, I know my husband would not have wanted something like this. ~~~~~. And my kids… now have this picture in their head and I have this picture in my head, that I don't see how that's going to help right now and I don't feel like that you've helped me very much with this either. So, after talking to my kids, while you were out of the room, I have decided that no, we do not want this and. ~~~~. That is what I have decided. Thank you.

Doc: Okay, if that's what you think is best.

SP: No! That's what I KNOW is best. The language that you've presented with for me did not help. That is what I've decided. I do not want this. We do not want this. So, thank you very much, but the answer is no.

Doc: Okay.

< Feedback page >
Narration: Narration: Narration: If Mrs. Lee seemed uncertain about declining, Dr. Fullerton might have gently asked Mrs. Lee to reconsider and discussed the benefits of an autopsy. However, Mrs. Lee's decision was firm and even if Dr. Fullerton's intention was to fully respect Mrs. Lee's decision, the tone of her response sent the wrong message to Mrs. Lee. Often families will not know what to do next. Perhaps Mrs. Lee would have appreciated if Dr. Fullerton let her know that the next step would be making arrangements for the funeral and that hospital staff could help Mrs. Lee.

< *Key point summary* >
Once the family decides to decline…
- Respect the family's decision.
- Suggest making funeral arrangements
- Help them contact the admitting office

When autopsy results could be crucial for the family…
- Listen and observe the family's non-verbal cues to gauge comfort levels.
- Gently suggest reconsidering only if the family seems unsure of their decision.

Narration: What if Mrs. Lee decides to request an autopsy for Mr. Lee? Dr. Fullerton would respond to Mrs. Lee's decision by…

< 8. How to respond when the family agrees >

1. Giving Mrs. Lee time to read and sign the autopsy consent form, while staying in the room to answer any questions. (Neutral)

2. Going through the entire autopsy consent form together with Mrs. Lee, making sure Mrs. Lee reviews everything on the form. (Great)

3. Handing over the autopsy consent form so that Mrs. Lee can sign before proceeding to making arrangements for the funeral. Dr. Fullerton completed the form and submitted it for Mrs. Lee. (Poor)

Great #8

SP: I mean, I……so…. (sigh) I took some time. I let my kids know what happened. That their father has died. They are as confused as I am. So, we have decided that we would like an autopsy. But we would like him to be treated very respectfully, so we can have an open casket. Please. Just take good care of him please.

DOC: Of course. Of course.

SP: …and let us know what happened to him. Thanks.

DOC: I do hope and think that this will provide more information and just one thing that I may not have mentioned earlier is that if you have an open casket, it will not be apparent that he had an autopsy done. All of those areas will be covered up.

SP: Okay. Thank you.

DOC: Of course. I do have a consent form here that I am going to need you to sign. If it's okay with you, can I read through it with you and go through the main points, so you are comfortable with this?

SP: Sure…

DOC: Okay. So as we start…

< *Feedback page* >
Narration: Dr. Fullerton read through the whole consent document with Mrs. Lee and made sure she understood every line. It is important that the 'next of kin', in our case Mrs. Lee, is fully aware of the contents of the consent form. By reviewing the entire form together with Mrs. Lee, Dr. Fullerton made sure Mrs. Lee did not misunderstand anything and was able to make an informed decision for her husband.

Neutral #8

SP: So I have thought about it and my kids are really upset they want to know what's going on, what happened… Yes, I think we will feel much better. I will feel much better and… you know, maybe it would be good for us to go ahead and have the autopsy done. So that is what we have decided.

DOC: Oh, good. I am really glad to hear that. That's great news. Here is a consent form that needs to be completed. Here, let me hand it over to you and then you can get started with it.

SP: Okay. Thank you.

< *Feedback page* >
Narration: It is important that the 'next of kin', in our case Mrs. Lee, is fully aware of the contents of the consent form. When reviewing the form on her own, Mrs. Lee may unknowingly misunderstand some details. Leaving families to review the form on their own may lead to wrong signators or uninformed decisions.

Poor #8

SP: So, you're saying that, this will help find out what happened to my husband. You know what, just give me the paper. I'll sign it because I really want to… I don't want to talk.

Doc: Okay, you see, just sign right down there.

SP: I don't want to talk. I don't want to talk anymore. Here.

Doc: Thanks.

< *Feedback page* >
Narration: Dr. Fullerton leaves the room with a consent. However, did Mrs. Lee understand the consent form? It is important that the 'next of kin', in our case Mrs. Lee, is fully aware of the contents of the consent form. Families signing without reviewing the form may lead to wrong signators or uninformed decisions.

< *Key point summary* >
Once the family decides to request an autopsy…
- Determine the right 'next of kin' (next of kin hierarchy table).
- Go through the entire consent form together.
- Suggest making funeral arrangements
- Help them contact the admitting office
- Explain that autopsies do not prevent open casket viewings or organ donation.

<GENERAL RECAP>

Narration: We have followed Dr. Fullerton and have made important observations. When asking for an autopsy consent…
- Don't rush and give the family time and space.
- Mention how the autopsy can benefit the family.
- Listen, observe, and demonstrate empathy.
- Help the family give informed consent; not just their signature.
- Remember families can request to limit the autopsy.

Appendix F: Standardized Patient request form.

Project description

I am designing an online training module for clinicians demonstrating the process of *asking for an autopsy consent* from the patient's family.

Objective for SP session

I plan to *video record* the conversation and interactions that may happen between a clinician and the patient's family during the process. I am seeking one Standardized Patient to role play the *deceased patient's spouse*, conversing with and reacting to the clinician.

Background scenario

A patient passed away unexpectedly and the clinician is trying to ask for an autopsy consent. *The patient's spouse (SP) is grieving while trying to process everything that is happening.* The clinician will attempt to deliver necessary information while showing either 1) clinically empathetic responses, 2) neutral responses, or 3) insensitive responses, which the SP will react differently depending on the clinician's script. The conversation will take place in an office setting with the clinician and SP facing each other. There will be no physical contact. We are aiming for a timeless scenario, so COVID-19 will not be addressed in the scenario.

Specific requests for SP

Age: 40 y.o. or older
Gender: Female
Nationality: Any
Emotion level within scenario: Expressive

Filming specifications

Date: One half day between February 25 to March 7th.
Duration: 3 ~ 4 hours.
Takes: 3 takes total (1 take for each response).
Script: Short script with general directions. SP is welcomed to improvise. We wish to see some nonverbal cues, facial expressions, and body language.
Location: We request the SP travel to a conference room located on the Johns Hopkins Medical campus. Parking provided.
Equipment: SP does not have to worry about preparing

COVID-19 pre-cautions

Filming location: Appropriately ventilated space to accommodate 4 persons: 2 SP and 2 videographers
Masks: We prefer the SP to act without a mask during actual filming. Everyone except the person talking will have their masks on.
Social distancing: The SP, clinician and videographers will be at least 6 ft apart for the filming.

Compensation

Pre-filming interview: 15 ~ 20minute interview via Zoom. Gift card.
Filming: Hourly rate negotiable.

Appendix G: Standardize Patient Zoom interview questions.

1. How long you've been SP?
2. Have you worked on death bereavement projects?
3. How comfortable are you with showing emotion?
4. Due to COVID, the clinician will be 6 ft away.
   Would it be possible to react as naturally as possible?
5. We want emotional responses, but not to the point where conversations cannot progress.
6. We are welcoming the SPs to improvise.
7. Do you have any questions?
8. Compensation negotiations.

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VITA

Sora Ji was born in the Seattle, Washington in 1992. She frequently visited her mother's lab as a child where she developed her early fascination for science – especially enjoying the colorful posters that explained them. She was particularly captivated by an illustration of a developing mouse embryo that combined decades of research and discovery. Intrigued by the narrative, she continued to develop her lifelong interest in science and art even after her family moved to South Korea when she was eight years old.

Sora received her Bachelor's degree in biology at the University of Wisconsin Madison in 2015. She continued to pursue research and received her Master's degree in brain and cognitive sciences in 2018 at the Daegu Gyeongbuk Institute of Science and Technology in South Korea. During both degrees, she received honorable academic and research scholarship awards, suggesting she should continue pursuing research. However, she finally decided to admit her undeniable passion for art and storytelling that has always exceeded her interest in research.

Sora decided to become an artist; however, she held onto her fascination for science. Through her experience as a researcher, she recognized the importance of public interest to drive support and funding for scientific research and medical development. She already knew by experience how to attract interest: an intriguing story with captivating visuals. This realization fueled her interest in medical and biological visualization, leading her to apply to the medical and biological illustration graduate program at Johns Hopkins University.

Currently, Sora is a second-year medical and biological illustration graduate student at the Johns Hopkins University. She had the honor of receiving both the Vesalius Trust Research Grant and the Inez Demonet Scholar award. She aims to promote public interest in medicine and science through her storytelling and visuals – especially about memory and space medicine. Her goal is to help clients tell their best story so that the public can explore, understand, and celebrate the magnificent knowledge and the incredible discoveries that benefit our world. Sora Ji will receive her Master's degree in Medical and Biological Illustration in May, 2021.